

## References

[Back to contents](#)

1. Royal College of Paediatrics and Child Health CHR-UK Programme of Work at the MRC Centre of Epidemiology for Child Health, University College London Institute of Child Health. September 2013. Overview of Child Deaths in the four UK countries. [https://www.rcpch.ac.uk/system/files/protected/page/CHRUUK\\_Module%20A%20low%20res%20\(2\).pdf](https://www.rcpch.ac.uk/system/files/protected/page/CHRUUK_Module%20A%20low%20res%20(2).pdf)
2. CerebralPalsy.org.uk.2016 <http://www.cerebralpalsy.org.uk/cerebral-palsy.html>
3. Scope. 2016. Overview of cerebral palsy. <http://www.scope.org.uk/support/families/diagnosis/cerebral-palsy>
4. NHS Choices. 2016. Cerebral palsy. <http://www.nhs.uk/conditions/cerebral-palsy/>
5. DiFazio RL, Harris M, Vessey JA et al. Opportunities lost and found: Experiences of patients with cerebral palsy and their parents transitioning from paediatric to adult healthcare. *Journal of Paediatric Rehabilitation Medicine* 2014; 7(1): 17-31
6. Alriksson-Schmidt A, Hagglund G, Rodby-Bousquet E et al. Follow-up of individuals with cerebral palsy through the transition years and description of adult life: The Swedish Experience. *Journal of Paediatric Rehabilitation Medicine* 2014; 7(1): 53-61
7. Hamdani Y, Proulx M, Kingsnorth S et al. The LIFEsan model of transitional rehabilitative care for youth with disabilities: Healthcare professionals' perspectives on service delivery. *Journal of Paediatric Rehabilitation Medicine* 2014; 7(1): 79-91
8. Tsybina I, Kingsnorth S, Maxwell J et al. Longitudinal Evaluation of Transition Services ("LETS Study"): protocol for outcome evaluation. *BMC Pediatrics* 2012; 12-51
9. Liptak GS. Health and well being of adults with cerebral palsy. *Current Opinion in Neurology* 2008; 21(2): 136-142
10. National Institute for Health and Care Excellence Clinical guideline [NG43]: Transition from Children's to adult services. Published 2016. <https://www.nice.org.uk/guidance/ng43>
11. A National Clinical Strategy for Scotland. 2016. <http://www.gov.scot/Publications/2016/02/8699>
12. Herrett E, Gallagher AM, Bhaskaran K et al. 2015. Data Resource Profile: Clinical Practice Research Datalink (CPRD), *International Journal of Epidemiology* 2015; 44 (3) 827-836. <http://academic.oup.com/ije/article/44/3/827/632531>
13. Methodology for creation of the HES Patient ID (HESID). [http://www.hscic.gov.uk/media/1370/HES-Hospital-Episode-Statistics-Replacement-of-the-HES-patient-ID/pdf/HESID\\_Methodology.pdf](http://www.hscic.gov.uk/media/1370/HES-Hospital-Episode-Statistics-Replacement-of-the-HES-patient-ID/pdf/HESID_Methodology.pdf)
14. Meeraus WH, Petersen I, Gilbert R. 2015. Association between antibiotic prescribing in pregnancy and cerebral palsy or epilepsy in children born at term: a cohort study using the health improvement network. *PLoS One*; 10(3)
15. The NCEPOD Classification of Intervention. <http://www.ncepod.org.uk/classification.html>
16. Platt MJ, Krageloh-Mann I, Cans C. Surveillance of Cerebral Palsy in Europe: reference and Training Manual. *Medical Education* 2009; 43: 495-496
17. NHS England's Five Year Forward View. 2014. <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
18. Next Steps on the NHS Five Year Forward View. 2017. <http://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf>
19. National Institute for Health and Care Excellence (NICE) Clinical guidelines [NG62]: Cerebral palsy in under 25s: assessment and management. Published January 2017. <http://www.nice.org.uk/guidance/ng62>
20. Bosanquet M, Copeland L, Ware R et al. A systematic review of tests to predict cerebral palsy in young children. *Dev Med Child Neurol.* 2013; 55:418-426
21. The American Academy of Neurology: Guideline: Focus on Neuroimaging of Premature and Low Birth Weight Babies. Published June 2002. <http://www.aan.com/PressRoom/home/PressRelease/77>
22. Horridge KA, Johnston J, Phatak V et al. Magnetic resonance imaging of the brain in children and young people with a cerebral palsy: who reports matters? *Dev Med Child Neurol* 2011; 53(4):375-377
23. General Medical Council. Duties of a Doctor. Published 2013. [http://www.gmc-uk.org/guidance/good\\_medical\\_practice/duties\\_of\\_a\\_doctor.asp](http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp)
24. Her Majesty's Government and the Department of Health (England). 2013. NHS Constitution. <http://www.gov.uk/government/publications/the-nhs-constitution-for-england>
25. Jackson JL, Chamberlain J, Kroenke K. Predictors of patient satisfaction. *Soc Sci Med.* 2011; 52: 609–20

## REFERENCES

---

26. Council for Disabled Children: Emergency Healthcare Plans <https://councilfordisabledchildren.org.uk/our-work/health-and-wellbeing/practice/emergency-healthcare-plans>
27. Disability Matters: Advanced Care Planning Matters. <http://www.disabilitymatters.org.uk/Component/Details/468840>
28. CIPPS <http://apcp.csp.org.uk/documents/cpip-uk-training-manual-dvd>
29. National Institute for Health and Care Excellence (NICE) Clinical guideline [CG145]: Spasticity in children and young people with non-progressive brain disorders. Management of spasticity and co-existing motor disorders and their early musculoskeletal complications. Published July 2012. <https://www.nice.org.uk/guidance/cg145>
30. Palisano RJ, Rosenbaum P, Bartlett D et al. Content validity of the expanded and revised Gross Motor Function Classification System. *Dev Med Child Neurol* 2008; 50: 744–50
31. Meehan E, Reid SM, Williams K, et al. Hospital admissions in children with a cerebral palsy: a data linkage study. *Dev Med Child Neurol*. 2017;59(5):512-519
32. Janssens A, Williams J, Tomlinson R et al. Health Outcomes for Children with Neurodisability: what do professionals regard as primary targets? *Arch Dis Child*. 2014;99(10):927-32
33. Jayanath S. Parent-reported pain in non-verbal children and adolescents with cerebral palsy, *Dev Med Child Neurol*. 2016;58(4)395-401
34. Dickinson HO, Parkinson KN, Ravens-Sieberer U et al. Self-reported quality of life of 8–12-year-old children with cerebral palsy: a cross-sectional European study. *Lancet* 2007; 369: 2171–8
35. Parkinson K, Gibson L, Dickinson H et al. Pain in children with cerebral palsy: a cross-sectional multicentre European study. *Acta Paediatr* 2010; 99: 446–51
36. Fauconnier J, Dickinson HO, Beckung E et al. Participation in life situations of 8–12 year old children with cerebral palsy: cross sectional European study. *Br Med J* 2009;338:b1458
37. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities. 2013. University of Bristol. [www.bristol.ac.uk/cipold/fullfinalreport.pdf](http://www.bristol.ac.uk/cipold/fullfinalreport.pdf)
38. MENCAP. 2007. Death by Indifference. <https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>
39. Sullivan PB, Juszczak E, Bachlet AM et al. Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Dev Med Child Neurol* 2004; 46:796–800
40. Fung EB, Samson-Fang L, Stallings VA et al. Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *J Am Diet Assoc* 2002; 102:361–73
41. Dahlseng MO, Finbraten AK, Juliusson PB et al. Feeding problems, growth and nutritional status in children with cerebral palsy. *Acta Paediatr* 2012; 101: 92–8
42. National Confidential Enquiry into Patient Outcome and Death. 2017. Mental Health in General Hospitals: Treat as One. <http://www.ncepod.org.uk/2017mhgh.html>
43. Meehan E et al. Tertiary paediatric hospital admissions in children and young people with cerebral palsy. *Child: care, health and development* 2015; 41; 6: 928-937.
44. Meehan E, Williams K, Reid S M et al. Comparing emergency department presentations among children with cerebral palsy with general childhood presentations: a data linkage study. *Dev Med Child Neurol* 2017; 59: 1188–1195.
45. Royal College of Paediatrics and Child Health. Revised 2015. Facing the Future Standards for acute general paediatric services. <http://www.rcpch.ac.uk/sites/default/files/page/Facing%20the%20Future%20Standards%20web.pdf>
46. Royal College of Paediatrics and Child Health S.A.F.E 4: Recognising deterioration <http://www.rcpch.ac.uk/Safe-resource/4-recognising-deterioration>; NHS England Re-ACT- the Respond to Ailing Children Tool (2017) <https://improvement.nhs.uk/resources/re-act-respond-ailing-children-tool>
47. Pashuram et al. Multicentre validation of bedside paediatric early warning system score: A severity of illness score to detect evolving critical illness in hospitalised children. *Critical Care* 2011; 15: 3-10.
48. PICANet Annual Report. November 2016. Summary report: Paediatric Intensive Care Audit Network. [http://www.picanet.org.uk/Audit/AnnualReporting/PICANet\\_Annual\\_Report\\_2016\\_Summary.pdf](http://www.picanet.org.uk/Audit/AnnualReporting/PICANet_Annual_Report_2016_Summary.pdf)
49. Edwards JD, Houtrow AJ, Vasilevskis EE et al. Multi-institutional profile of adults admitted to paediatric intensive care units. *JAMA Paediatr* 2013; 167(5): 436-43
50. National Institute for Clinical Excellence (NICE) Clinical guideline [QS160]: End of life care for infants, children and young people. Published 2017. <https://www.nice.org.uk/guidance/qs160>

## REFERENCES

---

51. The Royal College of Anaesthetists and the Association of Anaesthetists of Great Britain and Ireland (2014) The NAP5 Activity Survey: Accidental Awareness during General Anaesthesia in the United Kingdom and Ireland. <http://www.nationalauditprojects.org.uk/NAP5report>
52. Tanner. S. Trends in paediatric Surgery in England. *Arch Dis Childs* 2007; 92:664–667
53. National Confidential Enquiry into Patient Outcome and Death. 2011. Are we there yet? Chapter 3; Rec 5.
54. Whiteman AR, Dhese JK, Walker D. The high risk surgical patient – a role for the multidisciplinary approach? *British Journal of Anaesthesia* 2016;116(3):311-314
55. Royal College of Anaesthetists. Guidelines for the Provision of Anaesthesia Services (GPAS) 2017: Guidelines for the Provision of Anaesthesia Services for Pre-operative Assessment and Preparation. Chapter 2. London. <https://www.rcoa.ac.uk/system/files/GPAS-2017-02-PREOP.pdf>
56. Royal College of Surgeons. Standards for Children's Surgery, 2013. [www.rcseng.ac.uk](http://www.rcseng.ac.uk)
57. The Association of Anaesthetists of Great Britain & Ireland the British Association of Day Surgery. Day Case and short stay: Guidelines Day case and short stay surgery 2. 2011. <https://www.aagbi.org/sites/default/files/Day%20Case%20for%20web.pdf>
58. Royal College of Anaesthetists. Guidelines for the Provision of Anaesthesia Services (GPAS) 2017: Guidance for Provision of Paediatric Anaesthetic Services. Chapter 10. London <http://www.rcoa.ac.uk/system/files/GPAS-2017-10-PAEDIATRICS.pdf>
59. Prosser. D. P, Sharma. N. Cerebral palsy and anaesthesia. *Continuing Education in Anaesthesia Critical Care & Pain*. 2010; 10(3)1: 72–76 <https://academic.oup.com/bjaed/article/10/3/72/478687>
60. General Medical Council. 2013. 0-18 years Guidance for all doctors [http://www.gmc-uk.org/guidance/ethical\\_guidance/children\\_guidance\\_index.asp](http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp); and General Medical Council. 2008. "Consent: Patients and Doctors making decisions together" [http://www.gmc-uk.org/guidance/ethical\\_guidance/consent\\_guidance\\_index.asp](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp)
61. Kings Fund and Department of Health. "No decision about me, without me". <https://www.england.nhs.uk/ourwork/pe/sdm/>
62. Social Care Institute for excellence. 2005. Mental Capacity Act. <https://www.scie.org.uk/mca/>
63. Age of Legal Capacity Act (Scotland) 1991 <https://www.legislation.gov.uk/ukpga/1991/50/section/1>; Children (Scotland) Act 1995) <https://www.legislation.gov.uk/ukpga/1995/36>
64. British Medical Association. Consent toolkit: 7. Children and Young People. <https://www.bma.org.uk/advice/employment/ethics/consent/consent-tool-kit/7-children-and-young-people>
65. Care Quality Commission. Brief Guide: Capacity and Competence in under 18s. <https://www.cqc.org.uk/sites/default/files/20151008%20Brief%20guide%20-%20Capacity%20and%20consent%20in%20under%2018s%20FINAL.pdf>
66. Association of Paediatric Anaesthetists of Great Britain and Ireland, Royal College of Anaesthetists and Royal College of Paediatrics and Child Health. 2013. Guidance for the administration of codeine and alternative opioid analgesics in children. <http://www.apagbi.org.uk/publications/apa-guidelines>
67. Malviya S, Voepel-Lewis T, Burke C et al. The revised FLACC observational pain tool: improved reliability and validity for pain assessment in children with cognitive impairment. *Paediatr Anaesth*. 2006 Mar;16(3):258-65
68. Association for Real Change. 2017. Scotland Transitions Forum: Principles of Good Transition 3. [http://scottishtransitions.org.uk/blank/wp-content/uploads/2017/01/Introduction\\_A4-version.pdf](http://scottishtransitions.org.uk/blank/wp-content/uploads/2017/01/Introduction_A4-version.pdf)
69. WHO guidance on Transition. <http://apps.who.int/adolescent/hiv-testing-treatment/page/Transition>
70. University Hospital Southampton NHS Foundation Trust, Southampton Children's Hospital. Transition to adult care: Ready Steady Go. <http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>
71. Cochrane Review: The Campbell Collaboration. 2015. <http://www.cochrane.org/uk/about-us/our-partners-and-funders/campbell-collaboration>
72. Wijlaars LPMM, Gilbert R, Hardelid P. Chronic conditions in children and young people: learning from administrative data. *Arch Dis Child*. 2016;101(10):881-885
73. Watson R, Parr J, Joyce C, et al. Models of transition care for young people with complex health needs: A scoping review. *Child Care Health Development*, 2011; 37(6), 780-91.

## REFERENCES

---

74. Binks JA, Barden WS, Burke TA et al. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of physical medicine and rehabilitation* 2007; 88(8), 1064-1073
75. Viner RM. National survey of use of hospital beds by adolescents aged 12 to 19 in the United Kingdom. *British Medical Journal* 2001;322:957-8
76. NHS England Children and Young People Health Outcome Forum 2011. <https://www.gov.uk/government/publications/independent-experts-set-out-recommendations-to-improve-children-and-young-people-s-health-results>
77. NHS England Children and Young People Health Outcome Forum 2013/14 report. <https://www.gov.uk/government/publications/independent-experts-set-out-recommendations-to-improve-children-and-young-people-s-health-results>
78. You're Welcome Pilot. 2017. Refreshed standards for Piloting. [http://www.youngpeopleshealth.org.uk/yourewelcome/wp-content/uploads/2017/02/YoureWelcome\\_RefreshedsStandards.pdf](http://www.youngpeopleshealth.org.uk/yourewelcome/wp-content/uploads/2017/02/YoureWelcome_RefreshedsStandards.pdf)
79. The Scottish Government. 2009. Better Health, Better Care: National Delivery Plan for Children and Young People's Specialist Services in Scotland. <http://www.gov.scot/resource/doc/257294/0076389.pdf>
80. Royal college of Physicians. 2015. Acute care toolkit 13: Acute Health for adolescents and young adults. <https://www.rcplondon.ac.uk/guidelines-policy/acute-care-toolkit-13-acute-care-adolescents-and-young-adults>
81. Action for Sick Children, EACH: Children's Charter. <http://www.actionforsickchildren.org/childrens-charter/>
82. NHS England. April 2016. General Practice Forward view. <https://www.england.nhs.uk/wp-content/uploads/2016/04/gpfv.pdf>
83. Toolkit to support the development of GP federations Kings Fund 2016. <https://www.kingsfund.org.uk/audio-video/primary-care-toolkit>
84. The GP Cluster. Scottish Government <http://www.gov.scot/Publications/2017/01/7911/4>
85. Care Quality Commission. 2014. From the Pond to the Sea: Children's Transition to Adult Services. [https://www.cqc.org.uk/sites/default/files/CQC\\_Transition%20Report\\_Summary\\_lores.pdf](https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf)
86. Palisano RJ, Rosenbaum P, Walter SD et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol.* 1997;39:214–223
87. Royal College of Physicians and Royal College of Nursing. 2012. Ward rounds in medicine: Principles for best practice.
88. The Scottish Government. 2000. Adults with Incapacity (Scotland) Act 2000. [http://www.legislation.gov.uk/asp/2000/4/pdfs/asp\\_20000004\\_en.pdf](http://www.legislation.gov.uk/asp/2000/4/pdfs/asp_20000004_en.pdf)
89. NHS Scotland. 2015. The Development of Record Linkage in Scotland: The Responsive Application of Probability Matching. [https://www.researchgate.net/publication/242473246\\_Chapter\\_The\\_Development\\_of\\_Record\\_Linkage\\_in\\_Scotland\\_The\\_Responsive\\_Application\\_of\\_Probability\\_Matching](https://www.researchgate.net/publication/242473246_Chapter_The_Development_of_Record_Linkage_in_Scotland_The_Responsive_Application_of_Probability_Matching)
90. The National Health Service Central Register (NHSCR) <https://www.nrscotland.gov.uk/statistics-and-data/nhs-central-register/about-the-register>
91. NHS Scotland. ISD Scotland Data Dictionary: CHI number. <http://www.ndc.scot.nhs.uk/Dictionary-A-Z/Definitions/index.asp?Search=C&ID=128&Title=CHI%20Number>
92. NHS Scotland. What is the Community Health Index (CHI)? <http://www.shsc.scot/media/16292/2014-12-16-what-is-the-community-health-index.pdf>

### Appendix 3

### Appendix 4

97. Demmler, J and Bandyopadhyay, A. (2014). Creation of the Dynamic Wales Electronic Cohort for Children (DWECC). Internal SAIL document available on request.
98. Available online at <http://www.wales.nhs.uk/sitesplus/documents/299/20150130-SOP-AM%202015-05%20Provider%20Spells-v1.pdf>

# Appendices

[Back to contents](#)

## Glossary

Term	Definition
A&E	Accident and Emergency
ADDE	Annual District Death Extract
AMH	Adolescent Mental Health
Ataxia	Lack of voluntary coordination of muscle movements that includes gait abnormality
BSO	Business Services Organisation
Cerebral palsy	Cerebral palsy is the name for a group of lifelong conditions that affect movement and co-ordination, caused by a problem with the brain that occurs before, during or soon after birth.
CI	Confidence interval
Congenital heart disease	This is a general term for a range of birth defects that affect the normal workings of the heart. The term "congenital" means the condition is present at birth.
Continuous Positive Airway Pressure - CPAP	A therapy that increases air pressure in the throat so the airway does not collapse when someone breathes in
CP	Cerebral Palsies
CPRD	Clinical Practice Research Database
CYP	Children and young people
Diplegia	Paralysis affecting symmetrical parts of the body
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
Dorsal rhizotomy	An operation used to improve spasticity (muscle stiffness)
Dyskinetic	Involuntary muscle movements
EDDS	Emergency Department Dataset
Emergency Health Care Plan/Emergency Care Summary	An Emergency Health Care Plan makes communication easier in the event of a healthcare emergency.
EPD	Enhanced Prescribing Dataset

## APPENDICES

Term	Definition
<b>Epilepsy</b>	Epilepsy is a common condition that affects the brain and causes frequent seizures. Seizures are bursts of electrical activity in the brain that temporarily affect how it works.
<b>Fundoplication</b>	An operation used to treat gastro-oesophageal reflux. It uses the top of the stomach to strengthen the sphincter so it is less likely to allow food, drink or acid to travel back into the foodpipe.
<b>Gastrostomy</b>	A gastrostomy is a feeding tube that is inserted directly into the stomach either surgically under direct vision (open or laproscopic), endoscopically (with a camera), or radiologically (x-ray guidance). A gastrostomy tube allows the delivery of supplemental nutrition and medications directly into the stomach.
<b>GMFCS levels</b>	Gross Motor Function Classification System - <a href="https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r">https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r</a>
<b>HBS</b>	Honest Broker Service
<b>Hemiplegia</b>	A condition that affects one side of the body
<b>HES (APC)</b>	Hospital Episode Statistics (Admitted Patient Care)
<b>HQIP</b>	Healthcare Quality Improvement Partnership
<b>HSCIC</b>	Health and Social Care Information System
<b>ICD</b>	International Classification of Diseases
<b>IMD</b>	Index of Multiple Deprivation
<b>ICD-10</b>	International Classification of Diseases, version 10
<b>Intrathecal baclofen</b>	Baclofen is delivered directly into the spinal fluid to help muscle stiffness
<b>ISAC</b>	Independent Scientific Advisory Committee
<b>ISD</b>	Information Services Scotland
<b>Levels of care (adults)</b>	Level 0/1: Normal ward care in an acute hospital Level 2: High Dependency Unit for patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from ICU Level 3: For patients requiring advanced respiratory support alone or monitoring and support for two or more organ systems.
<b>MHLDD</b>	Mental Health and Learning Disabilities Dataset
<b>Monoplegia</b>	Paralysis of a single limb

## APPENDICES

Term	Definition
NECCPS	North East Collaborative Cerebral Palsy Register
NHS	National Health Services
NICPR	Northern Ireland Cerebral Palsy Register
NIHS	Northern Ireland Health Service
NIRAES	Northern Ireland Regional Accident and Emergency System (South Eastern and Southern Trusts)
NISRA	Northern Ireland Statistics and Research Agency
NPD	National Pupil Database
NRS	National Records of Scotland
NSS	National Services Scotland
ONS	Office of National Statistics
OPDW	Outpatients Dataset Wales
<b>Paediatric critical/intensive care unit (PCCU/PICU)</b>	A discrete area within a ward or hospital where paediatric critical care is delivered.
<b>Paediatric levels of critical care</b>	<p>Level 1 PCCU: A discrete area or unit where Level 1 paediatric critical care is delivered. With Paediatric Critical Care Network agreement, CPAP for bronchiolitis may be initiated or continued in a number of Level 1 Paediatric Critical Care Units.</p> <p>Level 2 PCCU: A discrete area or unit where Level 1 and Level 2 paediatric critical care are delivered.</p> <p>Other than in specialist children's hospitals, Level 2 Units should be able to provide, as a minimum, acute (and chronic) non-invasive ventilation (both CPAP and BiPAP support) and care for children with tracheostomies and children on long-term ventilation, but should not be expected to deliver specialist Level 2 interventions such as ICP monitoring or acute renal replacement therapy. Within specialist children's hospitals, Level 2 Units may provide some or all of these additional specialist interventions.</p> <p>Level 3 PCCU: A unit delivering Level 2 and Level 3 paediatric critical care (and Level 1 if required). This unit may also be called a Paediatric Intensive Care Unit (PICU).</p>
PAS	Patient Administration System
PBPPHSC	Public Benefit and Privacy Panel for Health and Social Care
PEDW	Patient Episode Database for Wales
PHA	Public Health Agency
PICANet	Paediatric Intensive Care Audit Network

## APPENDICES

---

<b>Term</b>	<b>Definition</b>
<b>PYAR</b>	Person years at risk - the product of a number of people in a study times the amount of time they have spent in the study
<b>Quadriplegia/Tetraplegia</b>	Affecting all four limbs and the torso
<b>SAIL</b>	Secure Anonymised Information Linkage
<b>Scoliosis</b>	Scoliosis is where the spine twists and curves to the side
<b>Seriously ill patient</b>	A seriously ill patient is defined as a patient who requires or potentially requires critical care (level 3 care) whether their condition is medical, surgical or trauma related.
<b>SMR</b>	Scottish Morbidity Records
<b>SMR00</b>	Scottish Morbidity Records - Outpatients Attendances and Appointments
<b>SMR01</b>	Scottish Morbidity Records - General Acute Inpatient and Day Case
<b>SNOMED CT</b>	
<b>SNS</b>	Support Needs System
<b>SOSCARE</b>	Social Services Client Administration and Retrieval Environment
<b>Status epilepticus</b>	Convulsive seizures lasting more than 30 minutes
<b>Transition</b>	This describes the process of planning, preparing and moving from children's healthcare to adult healthcare. Transition should be a gradual process of change, which gives everyone time to ensure that young people and their families are prepared and feel ready to make the move.
<b>WDS</b>	Wales Demographic Service
<b>WECC</b>	Welsh Electronic Cohort of Children
<b>WLGP</b>	Wales Primary Care GP Dataset



## Appendix 1 – Resources

**NICE** National Institute for  
Health and Care Excellence

NG 62 - [Cerebral palsy in under 25s: assessment and management](#)

NG 43 - [Transition from children's to adults' services for young people using health or social care services](#)

CG 145 - [Spasticity in under 19s: management](#)



### **NCEPOD Classification of Intervention**

**IMMEDIATE** – Immediate life, limb or organ-saving intervention – resuscitation simultaneous with intervention. Normally within minutes of decision to operate.

**URGENT** – Intervention for acute onset or clinical deterioration of potentially life-threatening conditions, for those conditions that may threaten the survival of limb or organ, for fixation of many fractures and for relief of pain or other distressing symptoms. Normally within hours of decision to operate.

**EXPEDITED** – Patient requiring early treatment where the condition is not an immediate threat to life, limb or organ survival. Normally within days of decision to operate.

**ELECTIVE** – Intervention planned or booked in advance of routine admission to hospital. Timing to suit patient, hospital and staff.

Examples of tools covered in this report can be accessed through the links below:

**Pain scoring tools**

[Example of pain scoring tools](#)

Validated tool for the assessment and description of hand function

[The Manual Ability Classification System \(MACS\) for children with cerebral palsy](#)

Validated tool for description of eating and drinking ability

[Eating and Drinking Ability Classification System for Individuals with Cerebral Palsy \(EDACS\)](#)

**Emergency Health Care Plans**

[What is an Emergency Health Care Plan](#)

[Examples of Emergency Health Care Plans](#)

**Patient held passport**

[Example of a patient held hospital passport](#)

**Disability Matters**

[Training tools](#)

**GMFCS**

[GMFCS Scoring Tools](#)

**Surveillance of Cerebral Palsy in Europe**

[SCPE Reference & Training Manual](#)

## Appendix 2 - Routine National Data - approvals and costs and data preparation

### Timeline and costs

There was a continuous need to update and inform governance throughout the project. Duration from first contact to receipt of data was longest for NHS Digital data England. Special negotiations with the Northern Ireland Cerebral Palsy Register were approved and data received June 2017.

	Applied	Approved	Approved by	Received	Ready for analysis	Analysis complete
<b>UK</b>						
CPRD	Jan-16	May-16	Information Centre and the Independent Scientific Advisory Committee (ISAC) - Protocol No: 16_033R	Dec-16	Dec-16	Sept-17
PICANet	Nov-15	Oct-16	PICANet Clinical Advisory Group May-16	Feb-17		Jun-17
<b>ENGLAND</b>						
NHS DIGITAL (formally HSCIC)	Oct-15	Dec-16	Data Access Advisory Group	Jan-17	Oct-17	Dec-17
NECCPS	Dec-15	Feb-16	Regional Maternity Survey Office (RMSO)	Mar-16	Mar-16	Jun-16
<b>WALES</b>						
WALES	Sep-15		Information Governance Review Panel (IGRP) within the Secure Anonymised Information Linkage Databank (SAIL)	Jan-16	Jan 2017 (amended June 2017)	Sept-17

## APPENDICES

	Applied	Approved	Approved by	Received	Ready for analysis	Analysis complete
<b>SCOTLAND</b>						
SCOTLAND	Nov-15	April-16	Privacy Advisory Committee (PAC), consisting of medical professionals and general public	Aug-16	June-17	Nov-17
<b>NORTHERN IRELAND</b>						
NORTHERN IRELAND	Feb-16	Jul-16	Honest Broker Service (HBS) within the BSO	Dec-16 Mar-17 (SOSCARE/ Mortality/ Prescribing)	June-17	Dec-17
NICPR	Aug-16	Oct-16	Research governance at Queen's University, Belfast	Mar-16	Mar-16	Jun-16

### Costs for data

The costs charged by data providers to extract the data ranged considerably. Costings are outlined in the table below. These costs do not include updates or renewal of licenses.

Data source	Cost
<b>SAIL</b>	£500 base costs for access to SAIL data plus £81,197 (includes SAIL analyst time for preparation of Wales, Scottish, Irish and NHS Digital datasets for analysis, data storage, infrastructure and access by team members for all other data sets)
<b>NHS Digital</b>	£18,100 + VAT
<b>ISD</b>	£3,322
<b>HBS</b>	No charge
<b>CPRD</b>	£30,000 towards Cardiff License
<b>PICANet</b>	No charge
<b>NECCPS</b>	No charge
<b>NICPR</b>	No charge

## Appendix 3 - Data preparation and Linkage

### 1. SAIL Databank and NHS Wales Informatics Service – Welsh data See Appendix 4

### 2. NHS Digital (formerly the Health and Social Care Information Centre) – English data *Generating the Health Episode Statistics Identifier (HESID)*

The method for the creation of the HESID is discussed in detail in a methodology document published by Health and Social Care Information Centre (HSCIC).<sup>13</sup> In summary, the HESID is created by applying a matching algorithm which assesses various combinations of the NHS number, date of birth, sex, postcode, provider code and local patient ID variables. These fields are combined to create a patient key for each row of data. An individual HESID may match to more than one patient key, for example where they have moved house, been treated under multiple provider codes or had more than one local patient ID, but a patient key can match to only one HESID. A HESID index contains the mapping between HESID and patient key. The matching process attempts to match the patient key for each row of data to the patient key held in the HESID index. It is carried out using three passes (attempts to match). The first pass centres on NHS number and requires exact match on NHS number and sex and at least partial match on date of birth. The second pass centres on local patient identifier (the unique individual number assigned by each hospital provider) and requires exact match on local patient identifier and provider code, postcode and sex and at least partial match on date of birth. The third pass centres on date of birth and requires and exact match on date of birth, sex and postcode. Where a match is obtained the match is created and the existing HESID assigned to the record. Where no match is obtained, a new HESID is created and added to the HESID index and assigned to the record.

#### **Information governance requirements**

Data received from NHS Digital are stored in an environment that allows complete separation from any other data. These data are stored in the Data Science Building UK Secure eResearch Platform (UKSeRP). This is to ensure that

backup and archive requirements are met, and to facilitate the deletion requirements stipulated by NHS Digital. Data extracts received from Scotland and Northern Ireland were stored within the SAIL Databank.

### 3. Honest Broker Service (HBS) for Health and Social Care (HSC) – Northern Irish data

Data linkage in Northern Ireland is based on Health and Care Number (HCN). This is a unique identifier within Northern Ireland for an individual person, and is allocated at birth. Some patients may not have an HCN (e.g. visitors to Northern Ireland). No probabilistic matching method is used in Northern Ireland and therefore data for individuals without an HCN number cannot be included in any extracts as it cannot be linked. It is possible that an individual may have more than one HCN, but this is very rare. There are systems in place to detect and merge potential duplicates and also to correct “false positives” where records deemed to be matching relate to different patients.

### 4. Information Services Division, NHS National Services Scotland – Scottish data

Detailed information regarding the history and processes of creating the unique ID is provided in this document.<sup>89</sup> The National Health Service Centre Register (NHSCR) is a centralised register containing a single record for “everyone who was born, or has died, in Scotland plus anyone else who is (or has been) on the list of a general medical practitioner in Scotland”.<sup>90</sup> It is a population register containing basic demographic information but holds very little clinical information.

The unique health record identifier in Scotland is known as the Community Health Index (CHI) number.<sup>91</sup> The CHI is a population register for all residents of Scotland. CHI numbers are issued at birth; visitors and short-term residents can be assigned a temporary CHI number if required. The CHI is based on data held in a number of regional CHI databases and controlled by the Scottish NHS Boards.<sup>92</sup> The CHI regional indexes “were initially compiled on an opportunistic basis and there was a general perception that there were gaps in its coverage and that there was a high proportion of duplicate records for people who had moved from one area of Scotland to another”.

It is possible for an individual on the NHSCR to be associated with more than one CHI number but the NHSCR contains only one record per individual. When creating linkage fields for health data, records containing the CHI number are matched against records held in the NHSCR and linked where a match is found (using either deterministic or probabilistic matching). The NHSCR is also updated to maintain a record of all CHI numbers associated with an individual NHSCR record and the current CHI number (or most recent number for those who have died or moved outside Scotland) is noted and, once encrypted, is used as the linkage field. Any records that cannot be matched are excluded from data extracts.

### **CPRD**

#### ***Person years at risk***

The basis for the calculations was CPRD's (anonymised) list of patients indicated to have data of an acceptable standard for research purposes who were aged 0 up to 25 at any point during the study period of 1 January 2004 to 31 December 2014. Each individual was included in the study for a period dependent on the patient's dates of birth, death (if relevant) and registration with a GP, and the dates of the last collection of data from the GP and when the GP's data met CPRD's quality standard. An individual's total time at risk within the study was then broken down by age band, year, gender and Index of Multiple Deprivation (IMD) quintile.

### **SAIL**

#### ***Person years at risk***

A file of [anonymised] patient identifiers comprised the cohort of patients aged 0 up to 25 *resident in Wales* at any point during the study period of 1 January 2004 to 31 December 2014. Not all GP practices in Wales (~70%) contribute to data to SAIL but SAIL's coverage of NHS secondary care outpatient and inpatient activity is complete. Data collection began either from GP registration or at study onset whichever was the later. Data collection ended at the end of registration with a SAIL GP, date of death, 25th birthday or the study end date, whichever was sooner. An individual's total time at risk within the study was then broken down by age band, year, gender and IMD quintile.

## Appendix 4 - The Secure Anonymised Information Linkage (SAIL) databank

### 1. Background and overview

The purpose of this document is to summarise the processes undertaken to create a denominator cohort of individuals born between specified dates, a series of case flags indicating presence or otherwise of conditions of interest/comorbidities, and a series of health activity extracts, which will together be used to answer the hypotheses put forward in the 0298 and 0463 project(s), for both the Cerebral Palsy (CP) and Adolescent Mental Health (AMH) arms of the project.

All tables provided to members of the project team have been project encrypted. This means that any field containing information relating to a single individual (such as a patient identification number) or an identifiable geographical or administrative feature (such as a GP practice) is encrypted with a key unique to each project.

This is a summary version of the project documentation. A full version is available which provides greater technical detail about the creation of specific variables, field names and source data.

### 2. Creation of the denominator cohort

#### **This table is named ALF\_COHORT\_TABLE\_V1\_0.**

The ALF Cohort Extract (the ALF Cohort) was created from three main data sources; the Welsh Demographic Service Dataset (WDS), the National Community Child Health Dataset (NCCH) and the Welsh Electronic Cohort for Children (WECC).

#### **Selection of main ALFs**

Anonymised Linkage Fields (ALFs) were extracted from WDS and NCCH (extracted separately and then merged to form a single ALF list) where the Week of Birth (WOB) was between 1/1/1979 and 31/12/2015. The study period is from 2004 to 2014 (calendar year) so the WOB selection ensures that there are individuals present in each year of the study period whose ages range from 0-25 years of age. All non-null ALFs were selected from WDS and NCCH.

From NCCH only ALFs with an ALF Status Code of 1, 4 or 39 were included; this excludes fuzzy matches where match probability is <0.5 and mirrors the WECC methodology. From NCCH, stillbirths were excluded. There are a greater number of null ALFs in NCCH in earlier years (>=4000 in 1988, around 1000-1500 in the 1990s, around 200 by 2004 and <100 by 2010).

In addition to the WDS and NCCH ALFs, the WECC dataset was searched and any ALFs in neither the WDS nor NCCH datasets were appended to the ALF Cohort. These ALFs were flagged separately. The reason that there are ALFs in WECC but not in either WDS or NCCH is because WECC was created based on older versions of WDS and NCCH. These ALFs were in the older versions of WDS and/or NCCH but not in the most recent ones. They have been flagged so can be included or excluded as required.

Please note that as NCCH contains only births from 1998 onwards, for births prior to this time WDS is the only available source.

#### **Selection of supplementary ALFs**

The Patient Episode Database for Wales (PEDW), the Emergency Department Dataset for Wales (EDDS), the Outpatient Department Dataset for Wales (OPDW) and the Annual District Deaths Extract (ADDE) were searched for individuals who were not in WDS, NCCH or WECC but who had been in contact with one or more of these services (or who had died according to the ADDE) when they were under 25 years of age. Only those ALFs with a Welsh Local Super Output Area (LSOA) were included (those where the first character is 'W'). These are individuals who have never had a GP registration with a Welsh GP or appeared in the NCCH, but who have for some reason had at least one contact with Welsh health services. They may be short-term visitors to Wales or they may be resident but in temporary or insecure accommodation or be transient. It was felt important to capture these individuals, but they are supplementary to the main ALF Cohort. They are flagged within the ALF cohort so they can be easily identified and analysed separately.

There is no date of birth, gender or other demographic information available within the ALF cohort dataset for these individuals. This is because WOB is not a variable in the PEDW, EDDS, ADDE or OPDW datasets and an accurate WOB cannot be derived for these individuals as age is provided in years only. There are fields for age in years at time of activity (but not WOB), gender, LSOA etc for these individuals available in each of the activity extracts (see section 5).

### **Inclusion and creation of other variables**

The WDSO extract includes WOB, gender and date of death (DOD) and WDSO-specific variables are populated with these data for all ALFs in WDSO.

The NCCH extract included WOB, gender and DOD variables and also additional variables specific to the NCCH dataset, and NCCH-specific variables are populated with these data for all ALFs in NCCH. Variable details are in the full data specification document.

To each of these ALF extracts, the age/date at first GP registration was added. This was derived from WDSO and based on the WOB within each extract (e.g. the first registration date for the NCCH ALFs was based on the WOB as given for that ALF in NCCH). There is an age at first registration for NCCH and WDSO. This is important to note, as the WOB is not necessarily the same in WDSO and NCCH, which means the age at first registration for the same individual may be different according to WDSO and NCCH. Both fields are provided.

The WDSO and NCCH extracts include a number of ALFs with >1 Person ID (the ostensibly unique ID within each dataset) and also a number of Person IDs which have >1 ALF. These individuals have not been excluded but have been flagged so they can easily be identified and excluded if required (please refer to the full data specification document for details of field names).

For all ALFs present in the WECC dataset, selected WECC variables were appended into the ALF Cohort for each individual. Variable details are in the full data specification document.

Using the WECC prioritisation rules, combined WOB, gender and Date of Death (DOD) variables were created. These variables provide a master WOB, gender and DOD field for analysis purposes. This is necessary as the data held in WDSO and NCCH for these variables is sometimes inconsistent so it was felt that a standard approach was required. The priority orders are obtained from the WECC documentation.<sup>97</sup> Where the ALF was in the WECC extract, WECC values were taken. For all ALFs not in WECC the following priorities were applied:

For WOB the priority order is:

- a. WDSO
- b. NCCH
- c. Annual District Births Extract (ADBE)

For DOD the priority order is:

- a. ADDE
- b. NCCH
- c. WDSO

For gender the priority order is:

- a. WDSO
- b. ADBE
- c. ADDE
- d. NCCH

Flags were created to state whether an ALF was present in specified SAIL datasets, namely PEDW, Welsh Longitudinal General Practice events (WLGP), EDDS, OPDW and ADDE. Two levels of variable were created for each of these datasets: one to show whether the ALF had been present in the dataset prior to 25th birthday with an event date at any point in time (labelled as `ever_u25`), and one to show whether the ALF had been present in the dataset prior to 25th birthday AND where the event date was between 1/1/2004 and 31/12/2014 (the study period – labelled as `2004_14_u25`). Only those ALFs with a WOB available were attributed flags – this means that the ALFs which were derived from non WDSO/NCCH/WECC sources do not have flags present.

Variables were created to categorise ALFs according to age at time of first GP registration. Flags for registrations before the age of 0 (suggesting data quality issues), between 0 and 10, between 0 and 15 and between 0 and 17 were created. Variable naming convention for these variables is 'reg\_before\_X'.

Finally a variable was added to flag those ALFs where, according to NCCH the individual had a WOB which fell between the specified date range, but the data for that individual in WSD showed a WOB outside the range. As WSD takes precedence over NCCH according to the WECC rules, it may be necessary to exclude these individuals.

### 3. Creation of follow up time extract

Extracts were created to allow the calculation of follow up time for each individual. These extracts were created using stored procedures written by Dan Thayer, Senior Analyst in the SAIL Analyst Team. These procedures “clean” the data and produce an output based on a series of rules and criteria. Documentation for the GP Cleaner is available in a separate document. Two extracts were provided:

- **This table is named W\_OUTPUT\_GP\_CLEANER\_V1\_0.** The WLGP extract shows the patient’s GP registration history, with a row for each registration period with a GP. There is a variable to show whether each registration period for each ALF has data present in SAIL (where pre-agreed quality standards are met regarding the volume of data recorded by each practice). Where a patient has had two registration periods with the same GP, there will be two separate lines present, with different start and end dates. The practice codes have been encrypted, which means that the actual practice cannot be identified, but different practices can be distinguished from each other.
- **This table is named W\_OUTPUT\_ADDRESS\_CLEANER\_V1\_0.** The address extract shows the patient’s residential history, with a row for each period of residence at an address. This is based on the Unique Postcode Reference Number (UPRN) for an address which is used to create a Residential Anonymous Linkage Field (RALF) for each address. Start and end dates are provided for periods of residence at each address. Deprivation indicators have been added to this table. These give the Welsh Index of Multiple deprivation (WIMD) quintile and decile for each residence (based on the residence LSOA). The LSOA codes have been encrypted, which means that the actual LSOA cannot be identified, but different LSOAs can be distinguished from each other.

Please note that at present, due to problems with the WLGP data extract, there are a number of GP practices which do not have data for all patients; patients who died or were deregistered 18 months or more prior to the data extract date have been excluded from the extracts of some practices. It is hoped that this will be rectified in early 2017. When this happens a new extract will be provided.

There are a number of ALFs in the ALF cohort which are absent from the Address Cleaner table. This is where the ALF did not have a RALF in the WSD data (which is the source for the Address Cleaner output).

These tables can be joined to the ALF Cohort table and the activity tables using the ALF field. An outer join should be used (unless only the individuals in the cleaner table are required) as there are some individuals in the ALF cohort who are not in the GP Cleaner or the Address Cleaner tables.

### 4. Creation of alf cohort case flag extracts

The ALFs in the cohort list were used to create extracts from PEDW, EDDS, ADDE, OPDW and WLGP which allowed case flag variables to be created. These variables were based on lists of clinical codes grouped into conditions of interest/ comorbidities. International Classification of Diseases (ICD10) codes were used for PEDW, OPDW and ADDE. READ codes were used for WLGP and a combination of local (Wales-specific) codes and ICD10 codes were used for EDDS. The ICD10 and READ code lists were provided by the project team to SAIL. SAIL analysts provided summary output data based on provided code lists, in order to validate the lists, in order to create final validate lists of codes.

Where the codes for the condition of interest were present in the patient history, the ALF was flagged as ‘1’ in the variable field for that condition. Two levels of case flags were created; one set where the individual was under 25 at time of contact and where the contact was between 1/1/2004 and 31/12/2014, and another set where the where the individual was under 25 at time of contact and where the contact was at any point.

Please note that as EDDS data starts in 2009 flags for this dataset will capture only cases from 2009 onwards.



The flags were saved into separate tables for each dataset. It is very important to note that the case flag tables do not contain a full list of all ALFs in the cohort. They contain only ALFs where there has been contact with the specified service (e.g. only ALFs that have had an inpatient admission feature in the PEDW extract). In addition the PEDW and OPDW extracts will include only those ALFs where there has been at least one clinically coded contact. This means that where the entire ALF cohort is required, outer joins should be used when joining these tables to the main ALF cohort. The case flag tables on their own cannot be used to calculate denominators for the ALF cohort as they do not contain all ALFs (except where the required denominators are specific to the service type e.g. the proportion of all patients who have at least one clinically coded record in PEDW that have condition X).

These tables are named:

- W\_PROC1\_PEDW\_OUTPUT\_TABLE\_U25\_2004\_14\_YYYYMMDD
- W\_PROC1\_PEDW\_OUTPUT\_TABLE\_U25\_YYYYMMDD
- W\_PROC1\_OPDW\_OUTPUT\_TABLE\_U25\_2004\_14\_YYYYMMDD
- W\_PROC1\_OPDW\_OUTPUT\_TABLE\_U25\_YYYYMMDD
- W\_PROC1\_WLGP\_OUTPUT\_TABLE\_U25\_2004\_14\_YYYYMMDD
- W\_PROC1\_WLGP\_OUTPUT\_TABLE\_U25\_YYYYMMDD
- W\_PROC\_1\_EDDS\_FLAG
- W\_PROC\_1\_ADDE\_FLAG

These tables can be joined to other tables using the ALF field. Please bear in mind that the case flag tables do not include all ALFs in the cohort, and therefore an outer join may be required.

### 5. Creation of activity extracts from sail datasets

The ALF cohort was used to create extracts of contacts with services for all patients in the cohort. Extracts were created from PEDW, WLGP, EDDS, ADDE and OPDW datasets. These extracts contain every contact that the ALF has ever had with the service, with no date-related exclusion criteria. Dates are included in each extract so date can be extracted for specified periods as required. Each extract includes key variables from the dataset, including gender, age (or WOB if available), LSOA at time of contact, administrative variables relating to the contact, and then a series of variables which

contain 0/1 flags for presence or absence of a target clinical code. Please note that the WOB, gender and LSOA values in the extracts may differ from those in the ALF cohort, as they are derived from different sources. This may be where the patient given information different from that in the GP record e.g. the patient has moved to a new address but not notified their GP.

These tables can be joined using the ALF field. As with other tables, care should be taken when joining. Where joining to the ALF Cohort, if the full cohort is required then an outer join should be used as these tables do not contain the full ALF cohort, but only those ALFs that have had contact with the named service.

#### PEDW

**This table is named W\_PROC2\_PEDW\_ACTIVITY\_OUTPUT\_YYYYMMDD.** The PEDW extract contains a single row for each diagnosis code attributed to contacts for that individual. Contacts for each ALF are organised into Person Spells using the Person Spell Number created for SAIL by NWIS, using the agreed methodology.<sup>98</sup> The start and end dates for the Person Spell have been derived and are included as variables. For each Person Spell, the full list of ICD10 diagnosis codes and OPCS4 Procedure codes are available where they are present in the patient record (coding is not 100% so there are a small number of uncoded episodes).

#### PEDW OPER

**This table is named W\_PROC2\_PEDW\_OPER\_ACTIVITY\_OUTPUT\_YYYYMMDD.** The PEDW OPER table is identical to the PEDW table except that instead of a row per diagnosis code, there is a row per procedure (OPCS4) code.

#### OPDW

**This table is named W\_PROC2\_OPDW\_ACTIVITY\_OUTPUT\_YYYYMMDD.** The OPDW extract is a row per appointment. This includes appointments that were not attended by the patient (DNAs) and appointments that were cancelled (either by the hospital or by the patient). Administrative codes are present allowing new and follow up appointments and attendances, DNAs and cancellations to be distinguished. As with the PEDW extracts there is a row per diagnosis code.



## Appendix 5 - The role and structure of NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is an independent body to which a corporate commitment has been made by the Medical and Surgical Royal Colleges, Associations and Faculties related to its area of activity. Each of these bodies nominates members on to NCEPOD's Steering Group.

### ***Steering Group as at 8th March 2018***

Dr M Nathanson	Association of Anaesthetists of Great Britain and Ireland
Vacancy	Association of Surgeons of Great Britain and Ireland
Mr K Altman	Faculty of Dental Surgery, Royal College of Surgeons of England
Vacancy	Faculty of Public Health Medicine
Mr S Barasi	Lay Representative
Ms S Payne	Lay Representative
Dr J C Carey	Royal College of Anaesthetists
Dr K Ramachandran	Royal College of Anaesthetists
Dr J Butler	Faculty of Intensive Care Medicine
Dr C Mann	Royal College of Emergency Medicine
Dr A Tavaré	Royal College of General Practitioners
Mrs J Greaves	Royal College of Nursing
Mr T Hillard	Royal College of Obstetricians and Gynaecologists
Mr W Karwatowski	Royal College of Ophthalmologists
Dr I Doughty	Royal College of Paediatrics and Child Health
Dr L Igali	Royal College of Pathologists
Mr M McKirdy	Royal College of Physicians and Surgeons of Glasgow
Dr M Jones	Royal College of Physicians of Edinburgh
Dr A McCune	Royal College of Physicians of London
Dr M Ostermann	Royal College of Physicians of London
Dr M Cusack	Royal College of Physicians of London
Dr J Carlile	Royal College of Psychiatrists
Prof R McWilliams	Royal College of Radiologists
Mr W Tennant	Royal College of Surgeons of Edinburgh
Mr J Abercrombie	Royal College of Surgeons of England
Mr M Bircher	Royal College of Surgeons of England

### ***Observers***

Dr D Sharpstone	Coroners' Society of England and Wales
Mr J Campbell	Healthcare Quality Improvement Partnership

### **Trustees**

Professor L Regan – Chair | Dr D Mason – Honorary Treasurer | Mr I Martin | Ms J Barber | Professor R Endacott  
Professor T J Hendra

NCEPOD is a company, limited by guarantee (Company number: 3019382) and a registered charity (Charity number: 1075588) | Company Secretary Dr M Mason

### **Clinical Co-ordinators**

The Steering Group appoint a Lead Clinical Co-ordinator for a defined tenure. In addition there are 8 Clinical Co-ordinators who work on each study. All Co-ordinators are engaged in active academic/clinical practice (in the NHS) during their term of office.

Lead Clinical Co-ordinator:  
Dr V Srivastava (Medicine)

Clinical Co-ordinators:  
Dr M Juniper (Medicine)  
Dr K Wilkinson (Anaesthesia)  
Dr A P L Goodwin (Anaesthesia)  
Mr M Sinclair (Surgery)  
Dr S McPherson (Interventional Radiology)  
Dr K Horridge (Paediatrics)  
Dr M Allsopp (Adolescent Psychiatry)  
Dr A Michalski (Paediatric Oncology)

### **Lay Representatives**

NCEPOD has a number of lay representatives who assist in all aspects of NCEPOD's work.

Alice Joy | Ron Newall | Sharon North | Hayley Topping  
Nigel Buck | Constantinos Regas

### **Commissioning and supporting organisations**

The Clinical Outcome and Review Programme into Medical and Surgical Care is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Health and Social care division of the Scottish Government, the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS), the States of Jersey, the Bailiwick of Guernsey, and the Isle of Man.

Members of the Clinical Outcome Review Programme into Child Health Independent Advisory Group:

Stuart Logan | Claire Lemer | Sarah Bridges  
Jacqueline Cornish | Brian Godfrey | Linda Partridge  
Heather Payne | Paul Ramchandani | Maggie Rogers  
Prakash Thiagarajan | Verena Wallace | Jayne Wheway  
Dick Churchill | Susan Gallacher | Odette Burgess  
Carolyn Wilson

### **Members of the HQIP team**

James Campbell | Mirek Skrypak | Sue Latchem  
Sarah Walker

## APPENDICES

### Appendix 6 – Participation

Trust	Clinical Data Returned	Organisational Data Returned
Abertawe Bro Morgannwg University Health Board	Yes	Yes
Aintree Hospitals NHS Foundation Trust	Yes	Yes
Airedale NHS Foundation Trust	Yes	No
Alder Hey Children's NHS Foundation Trust	Yes	Yes
Aneurin Bevan University Health Board	Yes	No
Anglian Community Enterprise (ACE) CIC	NA	Yes
Ashford & St Peter's Hospitals NHS Trust	Yes	Yes
Barking, Havering & Redbridge University Hospitals NHS Trust	Yes	No
Barnet, Enfield and Haringey Mental Health NHS Trust	NA	Yes
Barnsley Hospital NHS Foundation Trust	Yes	Yes
Barts Health NHS Trust	Yes	Yes
Basildon & Thurrock University Hospitals NHS FoundationTrust	Yes	No
Bedford Hospital NHS Trust	Yes	No
Belfast Health and Social Care Trust	Yes	Yes
Berkshire Healthcare NHS Foundation Trust	NA	Yes
Betsi Cadwaladr University Local Health Board	Yes	Yes
Birmingham Community Healthcare NHS Trust	NA	Yes
Birmingham Women's and Children's NHS Foundation Trust	Yes	No
Black Country Partnership NHS Foundation Trust	NA	No
Blackpool Teaching Hospitals NHS Foundation Trust	Yes	Yes
BMI Healthcare	NA	No
Bolton Hospital NHS Foundation Trust	Yes	Yes
Bradford District Care NHS FoundationTrust	NA	Yes
Bradford Teaching Hospitals NHS Foundation Trust	Yes	Yes
Bridgewater Community Healthcare NHS Foundation Trust	NA	Yes
Brighton and Sussex University Hospitals NHS Trust	Yes	Yes
Buckinghamshire Healthcare NHS Trust	Yes	Yes
Burton Hospitals NHS Foundation Trust	Yes	Yes
Calderdale & Huddersfield NHS Foundation Trust	Yes	Yes
Cambridge University Hospitals NHS Foundation Trust	Yes	Yes
Cambridgeshire Community Services NHS Trust	NA	Yes
Cardiff and Vale University Health Board	Yes	Yes
Central and North West London NHS Foundation Trust	Yes	Yes
Central London Community Healthcare NHS Trust	Yes	NA
Chelsea & Westminster NHS Foundation Trust	Yes	No
Chesterfield Royal Hospital NHS Foundation Trust	Yes	Yes
City Hospitals Sunderland NHS Foundation Trust	Yes	Yes
Colchester Hospital University NHS Foundation Trust	Yes	Yes
Countess of Chester Hospital NHS Foundation Trust	Yes	Yes
County Durham and Darlington NHS Foundation Trust	Yes	Yes
Croydon Health Services NHS Trust	Yes	Yes
Cumbria Partnership NHS Foundation Trust	NA	Yes

## APPENDICES

### Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Cwm Taf University Health Board	Yes	Yes
Dartford & Gravesham NHS Trust	No	No
Derby Teaching Hospitals NHS Foundation Trust	Yes	Yes
Derbyshire Healthcare NHS Foundation Trust	NA	Yes
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Yes	Yes
Dorset County Hospital NHS Foundation Trust	Yes	Yes
Dorset Healthcare University NHS Foundation Trust	NA	Yes
East & North Hertfordshire NHS Trust	Yes	Yes
East Cheshire NHS Trust	Yes	Yes
East Coast Community Healthcare CIC	NA	Yes
East Kent Hospitals University NHS Foundation Trust	Yes	No
East Lancashire Hospitals NHS Trust	Yes	Yes
East Sussex Healthcare NHS Trust	Yes	Yes
Epsom and St Helier University Hospitals NHS Trust	Yes	Yes
Frimley Health NHS Foundation Trust	Yes	Yes
Gateshead Health NHS Foundation Trust	Yes	No
George Eliot Hospital NHS Trust	Yes	NA
Gloucestershire Care Services NHS Trust	NA	No
Gloucestershire Hospitals NHS Foundation Trust	Yes	No
Great Ormond Street Hospital for Children NHS Trust	Yes	Yes
Great Western Hospitals NHS Foundation Trust	Yes	Yes
Guy's & St Thomas' NHS Foundation Trust	Yes	Yes
Hampshire Hospitals NHS Foundation Trust	Yes	Yes
Harrogate and District NHS Foundation Trust	Yes	Yes
Heart of England NHS Foundation Trust	Yes	Yes
Hertfordshire Community NHS Trust	NA	Yes
Hillingdon Hospitals NHS Foundation Trust	Yes	Yes
Homerton University Hospital NHS Foundation Trust	Yes	Yes
Hounslow and Richmond Community Healthcare NHS Trust	NA	No
Hull and East Yorkshire Hospitals NHS Trust	Yes	Yes
Hywel Dda University Health Board	Yes	Yes
Imperial College Healthcare NHS Trust	Yes	Yes
Ipswich Hospital NHS Trust	Yes	Yes
Isle of Man Department of Health & Social Security	Yes	Yes
Isle of Wight NHS Trust	Yes	Yes
James Paget University Hospitals NHS Foundation Trust	Yes	Yes
Kent Community Health NHS Foundation Trust	Yes	Yes
Kettering	Yes	No
King Edward VII's Hospital Sister Agnes	Yes	Yes
King's College Hospital NHS Foundation Trust	Yes	No
Kingston Hospital NHS Trust	Yes	Yes
Lancashire Care NHS Foundation Trust	NA	Yes

## APPENDICES

### Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Lancashire Teaching Hospitals NHS Foundation Trust	Yes	Yes
Leeds Community Healthcare NHS Trust	NA	Yes
Leicestershire Partnership NHS Trust	NA	No
Lewisham and Greenwich NHS Trust	Yes	Yes
Lincolnshire Community Health Services NHS Trust	NA	No
Liverpool Community Health NHS Trust	NA	Yes
LIVEWELL South West	NA	No
Locala Community Partnerships CIC	NA	Yes
London North West University Healthcare NHS Trust	Yes	Yes
Luton and Dunstable Hospital NHS Foundation Trust	Yes	No
Maidstone and Tunbridge Wells NHS Trust	Yes	NA
Manchester University NHS Foundation Trust	Yes	Yes
Medway Community Healthcare CIC	NA	Yes
Medway NHS Foundation Trust	Yes	Yes
Mid Cheshire Hospitals NHS Foundation Trust	Yes	Yes
Mid Essex Hospitals NHS Trust	Yes	Yes
Mid Yorkshire Hospitals NHS Trust	Yes	No
Milton Keynes University Hospital NHS Foundation Trust	Yes	Yes
Newcastle upon Tyne Hospitals NHS Foundation Trust	Yes	Yes
NHS Ayrshire & Arran	No	No
NHS Borders	No	No
NHS Dumfries & Galloway	No	NA
NHS Fife	No	No
NHS Forth Valley	No	No
NHS Grampian	Yes	Yes
NHS Greater Glasgow & Clyde	No	No
NHS Highland	Yes	No
NHS Lanarkshire	Yes	Yes
NHS Lothian	No	No
NHS Tayside	No	No
NHS Western Isles	No	No
Norfolk & Norwich University Hospital NHS Trust	Yes	Yes
Norfolk Community Health & Care NHS Trust	NA	Yes
North Bristol NHS Trust	Yes	No
North Cumbria University Hospitals NHS Trust	No	Yes
North East London NHS Foundation Trust	NA	Yes
North Middlesex University Hospital NHS Trust	Yes	Yes
North Staffordshire Combined Healthcare NHS Trust	NA	Yes
North Tees and Hartlepool NHS Foundation Trust	Yes	Yes
North West Anglia NHS Foundation Trust	Yes	NA
Northampton General Hospital NHS Trust	Yes	Yes
Northamptonshire Healthcare NHS Foundation Trust	NA	Yes

## APPENDICES

### Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Northern Devon Healthcare NHS Trust	Yes	No
Northern Health & Social Care Trust	No	Yes
Northern Lincolnshire & Goole NHS Foundation Trust	Yes	Yes
Northumbria Healthcare NHS Foundation Trust	Yes	Yes
Nottingham University Hospitals NHS Trust	Yes	Yes
Nottinghamshire Healthcare NHS Foundation Trust	NA	Yes
Oxford Health NHS Foundation Trust	NA	No
Oxford University Hospitals NHS Foundation Trust	Yes	Yes
Pennine Acute Hospitals NHS Trust (The)	Yes	No
Pennine Care NHS Foundation Trust	NA	Yes
Plymouth Hospitals NHS Trust	Yes	Yes
Poole Hospital NHS Foundation Trust	Yes	Yes
Portsmouth Hospitals NHS Trust	Yes	Yes
Queen Victoria Hospital NHS Foundation Trust	Yes	Yes
Ramsay Health Care UK	NA	No
Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	Yes	Yes
Rotherham NHS Foundation Trust	Yes	Yes
Royal Berkshire NHS Foundation Trust	Yes	Yes
Royal Bournemouth and Christchurch Hospitals NHS Trust	NA	Yes
Royal Cornwall Hospitals NHS Trust	Yes	Yes
Royal Devon and Exeter NHS Foundation Trust	Yes	Yes
Royal Free London NHS Foundation Trust	Yes	Yes
Royal Liverpool & Broadgreen University Hospitals NHS Trust	Yes	Yes
Royal National Orthopaedic Hospital NHS Trust	Yes	Yes
Royal Orthopaedic Hospital NHS Foundation Trust	Yes	Yes
Royal Surrey County Hospital NHS Trust	Yes	Yes
Royal United Hospitals Bath NHS Foundation Trust	Yes	Yes
Salford Royal Hospitals NHS Foundation Trust	Yes	Yes
Salisbury NHS Foundation Trust	Yes	Yes
Sandwell and West Birmingham Hospitals NHS Trust	Yes	Yes
Sheffield Children's NHS Foundation Trust	Yes	Yes
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	Yes
Sherwood Forest Hospitals NHS Foundation Trust	Yes	Yes
Shrewsbury and Telford Hospitals NHS Trust	Yes	No
Solent NHS Trust	Yes	Yes
South Eastern Health & Social Care Trust	No	Yes
South Staffordshire & Shropshire Healthcare NHS Foundation Trust	Yes	NA
South Tees Hospitals NHS Foundation Trust	Yes	Yes
South Tyneside NHS Foundation Trust	Yes	Yes
South Warwickshire NHS Foundation Trust	Yes	Yes
Southend University Hospital NHS Foundation Trust	Yes	Yes
Southern Health & Social Care Trust	Yes	No



## APPENDICES

### Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Southport & Ormskirk Hospitals NHS Trust	Yes	Yes
St George's University Hospitals NHS Foundation Trust	Yes	Yes
St Helens and Knowsley Teaching Hospitals NHS Trust	Yes	Yes
Staffordshire & Stoke on Trent Partnership NHS Trust	NA	Yes
States of Guernsey Committee for Health & Social Care	NA	No
States of Jersey Health & Social Services	Yes	Yes
Stockport NHS Foundation Trust	Yes	Yes
Surrey & Sussex Healthcare NHS Trust	Yes	No
Sussex Community NHS Foundation Trust	Yes	Yes
Tameside and Glossop Integrated Care NHS Foundation Trust	Yes	Yes
Taunton & Somerset NHS Foundation Trust	Yes	Yes
The Dudley Group NHS Foundation Trust	Yes	Yes
The Leeds Teaching Hospitals NHS Trust	Yes	Yes
The Princess Alexandra Hospital NHS Trust	Yes	NA
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Yes	Yes
The Royal Marsden NHS Foundation Trust	Yes	No
The Royal Wolverhampton Hospitals NHS Trust	Yes	Yes
The University Hospitals of the North Midlands NHS Trust	Yes	No
The Walton Centre NHS Foundation Trust	Yes	Yes
Torbay and South Devon NHS Foundation Trust	Yes	Yes
United Lincolnshire Hospitals NHS Trust	Yes	Yes
University College London Hospitals NHS Foundation Trust	Yes	Yes
University Hospital Southampton NHS Foundation Trust	Yes	Yes
University Hospitals Birmingham NHS Foundation Trust	Yes	Yes
University Hospitals Coventry and Warwickshire NHS Trust	Yes	Yes
University Hospitals of Bristol NHS Foundation Trust	Yes	No
University Hospitals of Leicester NHS Trust	Yes	Yes
University Hospitals of Morecambe Bay NHS Trust	Yes	Yes
Walsall Healthcare NHS Trust	No	Yes
West Hertfordshire Hospitals NHS Trust	Yes	Yes
West Suffolk NHS Foundation Trust	Yes	Yes
Western Health & Social Care Trust	Yes	Yes
Western Sussex Hospitals NHS Foundation Trust	Yes	Yes
Whittington Health NHS Trust	Yes	Yes
Wirral University Teaching Hospital NHS Foundation Trust	Yes	Yes
Worcestershire Acute Hospitals NHS Trust	Yes	Yes
Worcestershire Health and Care NHS Trust	Yes	No
Wrightington, Wigan & Leigh NHS Foundation Trust	Yes	Yes
Wye Valley NHS Trust	Yes	Yes
Yeovil District Hospital NHS Foundation Trust	Yes	Yes
York Teaching Hospitals NHS Foundation Trust	Yes	Yes