Impact case study (REF3)

Institution: University of Leicester

Unit of Assessment: 4 Psychology, Psychiatry and Neuroscience

Title of case study: Improving developmental surveillance and educational support for children born preterm

Period when the underpinning research was undertaken: 2011 - present

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:
Samantha Johnson	Developmental Psychologist & Professor of Child Development.	01/11/2010 - present
Elizabeth Draper	Professor of Perinatal and Paediatric Epidemiology	02/02/1981 – present
Elaine Boyle	Associate Professor in Neonatal Medicine	01/11/2006 - present

Period when the claimed impact occurred: 2015 to present.

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

1. Summary of the impact (indicative maximum 100 words)
Leicester research has confirmed that children born preterm are at high risk of developmental problems, learning difficulties and special educational needs later in life. Our research has directly improved standards of follow-up care, both nationally and internationally, for this vulnerable population of children by:
(1) substantially informing clinical guidelines, including the National Institute for Health and Care Excellence guidelines on developmental surveillance;
(2) demonstrably altering clinical practice via the provision of an assessment tool designed to monitor the development of children born preterm - the Parent Report of Children's Abilities-Revised (PARCA-R);
(3) informing the creation of an e-learning resource that has significantly raised awareness of prematurity in the education sector and enhanced the quality of educational support for preterm born children and their families.

2. Underpinning research (indicative maximum 500 words)
Each year, 15 million babies are born preterm worldwide. Improved obstetric and neonatal care over recent decades means that many more babies survive than ever before, but for those born preterm, survival often comes at a cost. Interdisciplinary research conducted by Johnson and colleagues has shed light on the long-term developmental consequences of preterm birth.

Extremely preterm (EP) birth (before 28 weeks of gestation)
As part of the internationally renowned EPICure Studies, Johnson and colleagues have followed the development of cohorts of babies born EP from infancy to adulthood. They found that EP babies are more likely to go on to have neurodevelopmental disabilities and cognitive deficits than their term-born peers [**R1**] – problems which, they discovered, have a profound effect on later school performance. An assessment of EP children at 11 years of age revealed that they have poorer academic attainment and a markedly higher risk for special educational needs than children born at term [**R2**].

All preterm births (before 37 weeks of gestation)
University of Leicester (UoL) research has demonstrated that children born at all preterm gestations are at increased risk for developmental problems resulting in poor school performance. An NIHR-funded programme of research carried out at Leicester found that children born late and moderately preterm (LMPT), at 32 to 36 weeks of gestation, are at risk of long-term developmental problems. Compared to term-born children, LMPT children are at

increased risk of delayed cognitive and language development, poor social competence and autism spectrum symptoms [**R3**]. Other collaborative research found that all children born preterm have poorer academic attainment than their term-born peers [**R4**].

Creation of a 'Preterm Birth E-Learning Resource'
Crucially, Johnson and colleagues have shown that the prevalence of developmental disorders among EP babies born in 2006 compared with those born in 1995 did not decline, despite improved neonatal care and survival over this period [**R1**]. Coupled with increasing preterm birth rates, this means that there is a growing number of preterm children with developmental problems entering schools year on year. Despite this, research carried out by Johnson showed that education professionals have poor understanding of the long-term impacts of preterm birth and lack training in how to support these children in school. To improve educational support for this vulnerable population, Johnson and colleagues developed a new evidence-based 'Preterm Birth E-Learning Resource' to raise awareness of prematurity and equip staff with the skills they need to support children's learning. Use of the resource has been shown to significantly improve teachers' knowledge of the impact of preterm birth on children's development and their confidence in supporting preterm children in the classroom [**R5**].

Provision of a new developmental assessment tool
In 2004, Johnson and colleagues developed the PARCA-R questionnaire for identifying 2-year-old children at risk of delayed development. Since her appointment at Leicester in 2010, Johnson has led a substantial programme of research that has further developed the PARCA-R, including its use in different populations [**R6**]. Most recently, she led a study in which the PARCA-R became a norm-referenced, standardised test for use with *all* children in the general population, not just those born preterm [**R7**]. The questionnaire is available non-commercially from the University of Leicester with translations available in 14 languages, providing clinicians with a cost-effective tool for assessing children's cognitive and language development.

3. References to the research (indicative maximum of six references)
[**R1**]. Moore T, Hennessy EM, Johnson S, Draper ES, Costeloe KL, Marlow N. Neurologic and developmental outcome in extremely preterm children born in England in 2006 and 1995. BMJ 2012;345:e7961.
[**R2**]. Johnson S, Wolke D, Hennessy E, Marlow N. Educational outcomes in extremely preterm children: Neuropsychological correlates and predictors of attainment. Developmental Neuropsychology 2011;36:74-9.
[**R3**]. Johnson S, Evans TA, Draper ES, Field DJ, Manktelow BN, Marlow N, Matthews R, Petrou S, Seaton SE, Smith LK, Boyle EM. Neurodevelopmental outcomes following late and moderate prematurity: Population-based cohort study. Arch Dis Child Fetal Neonatal Ed 2015;100:F301-F308
[**R4**]. Quigley MA, Poulsen G, Boyle E, Wolke D, Field D, Alfirevic Z, et al. Early term and late preterm birth are associated with poorer school performance at age 5 years: a cohort study. Arch Dis Child Fetal Neonatal Ed. 2012 May;97(3):F167-173.
[**R5**]. Johnson S, Bamber D, Bountziouka V, Clayton S, Cragg L, Gilmore C, Griffiths R, Marlow N, Simms V, Wharrad HJ. Improving developmental and educational support for children born preterm: evaluation of an e-learning resource for education professionals. BMJ Open 2019;9(6):e029720.
[**R6**]. Blaggan S, Guy A, Boyle EM, Spata E, Manktelow B, Wolke D, Johnson S. A parent questionnaire for developmental screening in infants born late and moderately preterm. Pediatrics 2014;134:e55-e62.
[**R7**]. Johnson S, Bountziouka V, Brocklehurst P, Linsell L, Marlow N, Wolke D, Manktelow BN. Standardisation of the Parent Report of Children's Abilities-Revised (PARCA-R): a norm-referenced assessment of cognitive and language development at age 2 years. The Lancet Child and Adolescent Health 2019 Oct;3(10):705-712.

4. Details of the impact (indicative maximum 750 words)
Improved policy, guidelines, and standards of care for preterm children
Research conducted by Johnson and colleagues over the last decade has significantly increased awareness of the need for developmental surveillance throughout early childhood for children born preterm. This has had a direct and substantial impact on the development of

policy, guidelines, and standards of care for preterm-born children over the last five years, resulting in improved provision of developmental follow-up for this vulnerable population of children.

Nationally. In 2017, the National Institute for Health and Care Excellence (NICE) published the first guideline for the developmental follow-up of children born preterm [**E1**]. Specifically, UoL research directly contributed to the recommendations including, but not limited to, the following;
- the need for parents, healthcare and education professionals to be aware of the increased risk for developmental problems and disorders after preterm birth;
- the provision of a follow-up service that includes enhanced developmental surveillance for children born preterm, including developmental assessments at 2 and 4 years of age;
- methods to be used for identifying children with developmental problems in routine clinical follow-up at 2 and 4 years of age;
- routine use of the PARCA-R questionnaire to identify if a child is at risk of global developmental delay, intellectual disability or language problems at 2 years of age;
- the need to share information from routine clinical follow-up with education services;
- the need to record data from enhanced developmental surveillance, including PACA-R scores at 2 years of age, and from routine educational tests at 11 years of age in the National Neonatal Research Database.

Data published by the UK's National Neonatal Audit Programme (NNAP) of NHS neonatal services shows that the provision of developmental surveillance for children born <30 weeks of gestation—approximately **4,200 babies per year**—has improved since the NICE guideline was released, representing "an important increase after years of insignificant growth" [**E2**].

Internationally. Swedish National Neonatal Follow-up guidelines (2015) cite Johnson and colleagues' research, highlighting methods for assessing cognitive and language development and autism spectrum disorders in early childhood, and awareness of the increased risk for intellectual impairment and psychiatric disorders in preterm-born children [**E3**].

In 2018, The European Foundation for the Care of Newborn Infants (EFCNI) published the first 'Standards of Care for Newborn Health' to improve care for the 550,000 babies born preterm each year in the EU. Within the standards for 'Follow-up and Continuing Care', Johnson and colleagues' research was cited in the evidence underpinning recommendations including: cognitive, communication, attention, and social-emotional assessments to be conducted at 2 years of age; developmental progress, school readiness, and attention and social-emotional assessments to be conducted prior to school entry; and education professionals to receive training about the needs of children born preterm. To date, 108 healthcare societies and 50 parent organisations have formally supported the standards and EFCNI's call to action to improve newborn health [**E4**].

Improved clinical practice through use of the PARCA-R questionnaire
In 2017, NICE recommended that the PARCA-R be used to assess development at 2 years of age for all children born <30 weeks' gestation and all LMPT-born children with additional risk factors for developmental problems [**E1a**]. NICE reported that the evidence was "strongly in favour of the PARCA-R" as an effective tool to identify children with developmental delay and thus recommended that it should be used to "identify if the child is at risk of global developmental delay, learning disability (intellectual disability) or language problems" [**E1a**]. The importance of this assessment was recognised in the accompanying NICE Quality Standard (2018) which states that, "children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up appointments in the first year and an assessment at 2 years that focus on development" and that the assessment at 2 years should include use of the PARCA-R [**E1b**].

The PARCA-R is widely used nationally and internationally. In 2020, the PARCA-R was recommended by the International Consortium for Health Outcomes Measurement (ICHOM) to assess neurodevelopment, cognition and communication in all children born preterm and all hospitalised neonates. ICHOM standard sets recommend outcomes that matter most to parents

[**E7**]. Since May 2018, the PARCA-R has been downloaded 1194 times in 66 countries in Europe, Australia, America, Africa, and Asia [**E5**]. Data published by NNAP shows that the PARCA-R has significantly improved the quality of neonatal follow-up care in the UK. For example, in the 2019 report, the clinical team at Glasgow Royal Hospital for Children reported that, "since its introduction, 100% of families attending RHC clinic at two years corrected age, have completed a PARCA-R questionnaire" [**E2**], improving the quality of their service by enabling a "full, accurate developmental assessment" whilst "integrating families into the assessment process". In using the PARCA-R, their busy clinic now has "the ability to feedback to parents in a very meaningful way, relating their child's score to that of the general population" [**E6**].

PARCA-R also provides a robust method for remote developmental assessment. Considering COVID-19 and the need to limit face to face contact, the PARCA-R was recommended in 'Guidance for phone/video follow up clinics during COVID-19 Pandemic' for all developmental assessments at 2 years of age by the British Association for Neonatal Neurodevelopmental Follow-up (BANNFU) Group, a Special Interest Group of the British Association of Perinatal Medicine which exists to improve the long-term outcomes of all babies that have received neonatal care [**E12a**]. Accordingly, approximately 50% of all PARCA-R downloads have occurred since March 2020, with many users indicating this as the specific reason for accessing the tool, demonstrating the importance of the PARCA-R for continuing patient care globally [**E5**]. In 2020, the national Swiss Neonatal Network and Follow-Up Group (SwissNeoNet) adopted the PARCA-R to "undertake routine follow-up assessments at 24 months of children born very preterm or who have suffered from neonatal hypoxic ischaemic encephalopathy (approx. 1000 children per year) when face-to-face testing is not possible to ensure early diagnosis and intervention." In particular, they state that use of PARCA-R has given their 19 perinatal centres and 14 paediatric units "the capacity to continue delivering their services remotely, and more importantly ensuring that infant patient needs continue to be met during the pandemic" [**E12b**].

Improved educational support for children born preterm
Of the 60,000 babies born preterm each year in the UK, approximately 5,040 will go on to have special educational needs and many more will struggle in school. Johnson's research has demonstrated that the special constellation of developmental problems experienced by preterm-born children means that their difficulties may be missed in school. The use of the 'Preterm Birth E-Learning Resource' by educational professionals has led to increased awareness of the challenges preterm-born children face, enhanced support for preterm children in the classroom, and stronger relationships between schools and parents. The impact of the resource in improving patient and family care was recognised by the British Association of Perinatal Medicine (BAPM), which awarded the research team a Gopi Menon Award for Excellence in Research or Innovation for their development of the Preterm Birth E-Learning Resource [**E9d**]. The Smallest Things Premature Baby Charity launched their Prem Aware Award in 2020, inviting every school in the UK to become 'Prem Aware'. Core criteria of the award include: (1) senior school staff must undertake training using Johnson and colleagues' pre-term birth e-learning resource [**R5**] and this training must then be cascaded to all school teaching staff; (2) schools should amend their admission procedures to enquire about a child's birth history on admission to school for all new pupils [**E9a,b**].

To date, 13,800 individuals from 54 different countries have accessed the e-learning resource, including teachers, Early Years practitioners, educational psychologists, healthcare professionals and parents [**E8**], of which 65% of all users are education professionals. Use of the resource has led to changes in institutional policies and teaching practices, from revising school admission forms to developing individual learning plans and classroom seating plans. For example, South Wigston High School in Leicester now identifies and keeps a formal record of students born preterm. They have changed their admissions procedure to include "asking parents to indicate if their child was born pre-term and, if so, at what gestation" and "all classes now have specific seating plans which indicate where a child has been born preterm." This means that they "have been able to change how these children are supported in school as a direct consequence" of using the e-learning resource [**E9c**].

Importantly, the resource has strengthened relationships between schools and parents of preterm children by providing parents with the evidence they need to raise the issue of their child's birth history with the school. This is empowering for both the parent and child because it enables them to advocate for themselves using verified information for the first time. The Irish Neonatal Health Alliance (INHA) described the resource as life changing' for parents, "for the first time our … families have a comprehensive information resource which delivers much needed education to help families recognise the challenges that their child might face but more importantly it empowers families with the language and evidence to work with educators to access supports for their child" [**E10a,b**].

The research and the resultant uptake of the resource has enabled professionals and parents to support preterm born children at all stages of their educational journey, benefiting children in the long term. Geoff Miller, founder of adultpreemies.com and an adult survivor of extreme prematurity asserts that, "Given the importance and impact a child's academic, social and emotional outcomes can have on their career path and personal life to shape their lifetime outcomes, I would consider this resource to be as significant in improving the lifetime outcomes of children born premature as the introduction of CPAP or artificial surfactant" [**E11**].

5. Sources to corroborate the impact (indicative maximum of 10 references)
[**E1a**]. NICE Guidelines https://www.nice.org.uk/guidance/NG72
[**E1b**]. Quality Standard https://www.nice.org.uk/guidance/qs169
[**E2**]. NNAP Audit Programme 2019 Annual Report
[**E3**]. Swedish neonatal follow-up guideline: Nationella riktlinjer fo r uppfo ljning av neonatala riskbarn
[**E4**]. EFCNI standards of care: https://newborn-health-standards.org/
[**E5**]. PARCA-R downloads data
[**E6**]. Letter from Louise Leven, Glasgow Royal Hospital for Children.
[**E7**]. ICHOM Standard Set for Preterm and Hospitalized Newborns.
[**E8**]. Data on PRISM doenloads.
[**E9a**]. Evidence for impact in schools and teacher training: Prem Aware Award Criteria https://www.thesmallestthings.org/prem-aware-award
[**E9b**]. Preterm Birth E-Learning Resource for Education Professionals download data.
[**E9c**]. Testimonial: Teacher in charge of support for students born pre-term at South Wigston. High School.
[**E9d**]. BAMP Gopi Menon Awards https://www.bapm.org/pages/101-bapm-gopi-menon-awards
[**E10a**]. Letter from the Irish Neonatal Health Alliance part 1
[**E10b**]. Letter from the Irish Neonatal Health Alliance part 2
[**E11**]. Testimonial: Geoff Miller, founder of adultpreemies.com
[**E12a**]. Evidence for increased uptake during COVID: BANNFU Guidance.
[**E12b**]. Testimonial Swiss NeoNatal Network.