Institution: University of Warwick

Unit of Assessment: A4 - Psychology, Psychiatry and Neuroscience

Title of case study: Preterm and sick babies: Improving care standards and interventions in the UK and internationally

Period when the underpinning research was undertaken: 2009-2019

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:
Dieter Wolke	Professor of developmental psychology and individual differences	2006 – Present

Period when the claimed impact occurred: 2013-2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact (indicative maximum 100 words)

Professor Wolke's research into babies born preterm or sick has influenced care standards in the UK and internationally, leading to improved screening of developmental delays and educational outcomes. His work was instrumental in informing the European Foundation for the Care of Newborn Infants (EFCNI)'s standards of follow-up care in 2018; these have been endorsed and adopted by 170 professional and parent organisations across Europe. Wolke's work influenced UK Government guidelines on delayed school entry for preterm children. The PARCA-R (Parent Report of Children's Abilities-Revised) questionnaire, developed by Wolke and colleagues, is recommended as the most suitable and best validated tool for screening of all very preterm children at 2 years of age in NICE (2017) and other guidance. Available in 14 languages, it has been accessed by users in 67 countries. It became a major follow-up tool internationally when face-to-face assessment was not possible during the COVID-19 crisis.

2. Underpinning research (indicative maximum 500 words)

Preterm birth affects 15 million children, or 11% of births, every year worldwide. It is the major cause of childhood mortality and reduces life chances into adulthood. Wolke, with expertise in the birth, care and development of pre-term babies, drew on a number of longitudinal studies including the EPICure study, a national cohort of children in the UK born in 1995 at less than 26 weeks' gestation, and the Bavarian Longitudinal Study in Germany, which has followed very preterm children (<32 weeks' gestation) and full-term birth controls since 1985.

In the last decade Wolke and colleagues identified a distinct phenotype of difficulties experienced by children after preterm birth: multiple cognitive problems (intelligence, executive function), developmental coordination disorder, specific learning difficulties with mathematics, increased ADHD (ADD type) symptoms, anxiety and increased social problems (autism spectrum) and a more withdrawn personality **[3.1]**. These findings have been replicated, are universal and robust, and are identified as the *core areas* of psychological development affected by preterm birth that require monitoring in follow-up care.

In 2015 further research revealed an increased vulnerability for neurocognitive deficits in those born very preterm (<32 weeks gestation) and moderately preterm (32-33 weeks gestation) **[3.2]** e.g. being born at 30 weeks versus 31 weeks was related to a loss of 2.3 IQ points (IQ reduces for each week lost in very and moderately preterm children). In contrast, a loss of one week of gestation above 34 weeks was related to a loss of 0.3 IQ points per gestation week and was not significant.

From 2014 to 2019, Wolke and colleagues were the first to demonstrate that very preterm children do not outgrow cognitive problems, ADHD problems, educational and social difficulties by adulthood **[3.1, 3.3]**. They show lower neurodevelopmental plasticity than late preterm or term-born children: the functional deficits still detected in adulthood are related to alterations in brain growth and in brain networks, and cognitive functions with reduced cholinergic basal integrity **[3.4]**. Wolke showed that follow-up at the optimal time of 2 years of age is crucial for early identification of those with cognitive problems and for managing their care and schooling.

The findings on the high stability of cognitive deficits from 2 years into adulthood informed the development, testing and, later, standardisation of the PARCA-R (Parent Report of Children's Abilities-Revised) questionnaire, a parent-completed screening instrument of cognitive and language development at 24 months to triage intensive follow-up of preterm children **[3.5]**. It has been normed on over 6,500 children at 23-27 months, can be used across the gestation span and has been validated to detect early cognitive impairment not only by Wolke and colleagues but also by independent groups in other language versions.

In 2012, Wolke's general population longitudinal research established that summer-born (youngest in class) children are specifically disadvantaged compared to autumn-born (oldest in class) in academic tests **[3.6]**. Summer-born (before 31 August) preterm children are most disadvantaged as they are routinely admitted to school early, using their birth date rather than expected date of delivery, and should be permitted to delay school entry. In contrast, using data from the Bavarian Longitudinal Study, in 2015 Wolke showed that delaying school entry by a year for autumn-born pre-term children has no discernible advantage **[3.7]**. Rather, early identification of learning difficulties may aid improved educational pathways and success of all preterm children. They are the fastest growing group of special needs children **[3.8]** but teachers and educational psychologists in 2015 had very little knowledge of their specific needs and had received no training **[3.9]**.

3. References to the research (indicative maximum of six references) **Warwick = Bold**

All research papers were published in peer-reviewed journals

[3.1] Wolke, Dieter, Johnson, Samantha, J. **Mendonca, Marina** (2019) *The life course consequences of very preterm birth*. Annual Review of Developmental Psychology, 1, pp.69-92. doi: 10.1146/annurev-devpsych-121318-084804

[3.2] Wolke, Dieter, Strauss, Vicky Yu-Chun, Johnson, Samantha J., Gilmore, Camilla, Marlow, Neil and **Jaekel, Julia** (2015) *Universal gestational age effects on cognitive and basic mathematic processing: 2 cohorts in 2 countries.* The Journal of Pediatrics, 166 (6). 1410-1416.e2. doi:10.1016/j.jpeds.2015.02.065

[3.3] Linsell, Louise, Johnson, Samantha Ann, **Wolke, Dieter**, O'Reilly, Helen, Morris, Joan K., Kurinczuk, Jennifer J. and Marlow, Neil (2018) *Cognitive trajectories from infancy to early adulthood following birth before 26 weeks of gestation: a prospective, population-based cohort study.* Archives of Disease in Childhood, 103, pp.363-370. doi:10.1136/archdischild-2017-313414

[3.4] Grothe, Michel J., Scheef, Lukas, Bäuml, Josef, Meng, Chun, Daamen, Marcel, Baumann, Nicole, Zimmer, Claus, Teipel, Stefan, Bartmann, Peter, Boecker, Henning, **Wolke, Dieter**, Wohlschläger, Afra and Sorg, Christian (2017) *Reduced cholinergic basal forebrain integrity links neonatal complications and adult cognitive deficits after premature birth.* Biological Psychiatry, 82 (2). pp. 119-126. doi:10.1016/j.biopsych.2016.12.008

[3.5] Johnson, Samantha, Bountziouka, Vasiliki, Brocklehurst, Peter, Linsell, Louise, Marlow, Neil, **Wolke, Dieter** and Manktelow, Bradley N. (2019) *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 & Adolescent Health, 3(10). pp.705-712. doi:10.1016/S2352-4642(19)30189-0

[3.6] Quigley, Maria A., Poulsen, G., Boyle, E., **Wolke, Dieter**, Field, D., Alfirevic, Zarko and Kurinczuk, J. J. (2012) *Early term and late preterm birth are associated with poorer school performance at age 5 years: a cohort study.* Archives of Disease in Childhood - Fetal and Neonatal Edition, 97 (3). F167-F173. doi:10.1136/archdischild-2011-300888

[3.7] Jaekel, Julia, Strauss, Vicky Yu-Chun, Johnson, Samantha J., Gilmore, Camilla and **Wolke, Dieter** (2015) *Delayed school entry and academic performance: a natural experiment*. Developmental Medicine & Child Neurology, 57 (7). pp. 652- 659. doi:10.1111/dmcn.12713
[3.8] Johnson, Samantha J., Hennessy, Enid M., Smith, R. (Rebecca), Trikic, Rebecca, **Wolke, Dieter** and Marlow, Neil (2009) *Academic attainment and special educational needs in extremely preterm children at 11 years of age: the EPICure Study.* BMJ Archives of Disease in Childhood, Vol.94 (No.4). F283-F289. doi:10.1136/adc.2008.152793
[3.9] Johnson, Samantha J., Gilmore, Camilla, Gallimore, Ian, Jaekel, Julia and **Wolke, Dieter** (2015) *The long-term consequences of preterm birth: what do teachers know?* Developmental Medicine & Child Neurology, 57 (6). pp. 571-577. doi:10.1111/dmcn.12683.

From 2018-2020, Professor Wolke has been identified in Web of Science's Clarivate, 'Highly Cited Researcher' list that recognised the 0.1% of the world's researchers across 21 research fields who have been most frequently cited over the past decade.

Selected key grants

[G1] 2017 *PARCA-R Standardisation Project*. Action Medical Research. PI S Johnson (University of Leicester). Co-PI L Linsell, **D Wolke**, N Marlow, P B Brockelhurst, B N Manktelow. April 2018-April 2019. Total GBP70,698.00
[G2] 2016 *EPICure2 @ 11 - Outcome at 11 years for a national cohort of births between 22 & 26 weeks of gestation in England in 2006*. MRC. PI N Marlow (UCL); Co-PIs S Ourselin, J Hurst, J Morris**, D Wolke**, T Baldeweg, C Clark, S Johnson, J Cockcroft. September 2016-August 2019. Total GBP1,301,830.92
[G3] 2012 *EPICure @ 19 - the extremely preterm young adult*. Medical Research Council (MRC). PI: Prof Neil Marlow; Co-PI: S Ourselin**, D Wolke**, J K Morris, J Hurst, Xacier Golay, S Johnson. July 2012-June 2016. Total GBP2,272,981.00
[G4] 2009 *Bavarian Longitudinal Study - Social Adjustment and quality of life after very preterm birth*. Ministry of Science and Education (BMBF, Germany). PI (Germany): P Bartmann, University of Bonn, PI (UK): **D Wolke**. June 2009-June 2015. EUR949,232.00

4. Details of the impact (indicative maximum 750 words)

Professor Wolke and colleagues' cumulative research into babies born preterm or sick has had an impact on a large number of beneficiaries: policymakers, commissioners, healthcare professionals, education and social care services, parents and carers for children and young people born preterm, in the following ways:

Impact on European standards of care for follow-up of children or young people born preterm

Based on the politically identified need to achieve common standards of care and national guidelines across more than 30 countries, between 2013 and 2018 the European Foundation of the Care of Newborns and Infants (EFCNI) developed 96 standards of care **[5.1]**, of which 15 were concerned with follow-up and continuing care. Wolke chaired the international expert committee and edited these 15 standards. The chair of EFCNI confirms that "*Professor Wolke's research was instrumental in informing the Follow-up and Continuing Care standards. Several of his research publications, for example 'Universal gestational age effects on cognitive and basic mathematic processing', helped inform guidelines on cognitive development of infants born very preterm or those infants with risk factors*." **[5.2]**.

Wolke presented the standards to MEPs and interest groups at the European Parliament in Brussels in November 2018, highlighting the need for common standards of follow-up care across the member states, with approx. 650,000 preterm births per year. The standards have been endorsed by 120 healthcare professional societies and 51 parent organisations who support the call for action to implement them across Europe **[5.1]**.

National and international adoption of PARCA-R as a screening tool for neonatal care in child development clinics

Professional guidelines in the UK: Since 2017 the PARCA-R has been recommended by NICE in its guidelines, *Developmental follow-up of children and young people born preterm*, to screen for cognitive and language problems in the follow-up of very preterm children at 2 years (affecting 7,000 very preterm children per year in the UK) **[5.3]**.

International professional guidelines: EFCNI in one of its standards on 'motor and neurological follow-up assessment' recommends that healthcare professionals should *"start a service that uses parent reports using screening questionnaires - Ages and Stages Questionnaire or PARCA-R"* **[5.1]**. PARCA-R is the recommended patient outcome measure at 2 years in the Standard Set for Preterm and Hospitalised Newborn Health by the International Consortium of Health Outcomes Measurement (ICHOM), launched in August 2020 **[5.4]** (potentially 15 million newborns per year).

During the COVID-19 pandemic: The British Association of Neonatal Neurodevelopmental Follow Up recommended the use of PARCA-R for two years' review in their March 2020 guidance for telephone–video clinics **[5.5]**. The Swiss Society of Neonatology (SwissNeoNet), which hosts the official medical quality register for Switzerland's neonatal intensive care (level IIB) units and neonatal intermediate care (level III) units, also adopted the PARCA-R in 2020, when strict restrictions prevented face-to-face contact, to undertake routine follow-up assessments at 24 months of children born very preterm or who have suffered from neonatal hypoxic ischaemic encephalopathy (approx. 1,000 per year). The Co-ordinator of SwissNeoNet said: *"[PARCA-R] has given perinatal centres and paediatric units the capacity to continue delivering their services remotely and, more importantly, ensuring that infant patient needs continue to be met."* **[5.6a]**. In addition, in April 2020, the National Maternity Hospital, Dublin, started using the PARCA-R in place of their key follow-up tool - the Bayley Scale, with at least 120 children benefitting from the PARCA-R assessments **[5.6b]**.

Practitioners and parents: Since its standardisation (age-and sex-adjusted) in 2019, PARCA-R has been the preferred tool for cognitive screening of children at all gestations (630,000 per year in England and Wales) by healthcare professionals and parents. In December that year, the PARCA-R Technical and Interpretive Manual, describing the development and standardisation of the test and providing the norms tables needed to score the questionnaire by hand, was sent to all (204) neonatal units in the UK, reaching around 5,000 neonatal nurses, to support the test's use in clinical practice. Its non-standardised version is available in 14 languages and since May 2018 has been accessed by more than 1,200 users, mainly professionals and parents (71%), in 67 countries. **[5.7]**

PARCA-R is free to download and can be completed by parents in around 15 minutes, compared to 2 hours for the resource-intense standard developmental or IQ testing. As an example, PARCA-R was instrumental in Glasgow's Royal Hospital for Children (RHC)'s redesign of its neurodevelopment outpatient service in 2017. Before NICE guidance RHC had not used a standardised assessment at two years corrected age; for the last three years, 53 (100%) of families attending the clinic at two years corrected have completed a PARCA-R questionnaire **[5.8]**. The consultant neonatologist states that, "*Many children do not demonstrate their full potential within the outpatient clinic setting, particularly with language and cognition. The PARCA-R overcame this challenge while integrating families into the assessment process. Our families engaged well with the questionnaire, with every family completing the questionnaire in the first 2 years of its introduction."* **[5.8]**.

Improved awareness and measurement of outcomes by healthcare and educational professionals

National guidelines: Informed by Wolke's research, the NICE guidelines (2017) on the special needs of preterm children and lack of knowledge and training of teachers and educational psychologists recommended "*recording routine educational measures at key stage 2 (including special educational needs and disability) on an operational delivery network-wide basis, to allow educational outcomes at 11 years to be linked to neonatal information*." Healthcare professionals are also recommended to provide information about the risk and prevalence of developmental problems and disorders in babies born preterm to parents and carers, and offer to discuss this

with them **[5.3]**. Wolke's research informed the Swedish Neonatal Society's guidelines for the follow-up of neonatal risk babies (2015), highlighting the prevalence of extremely premature babies that need extra support at school age **[5.9]**.

Other guidelines for practitioners, parents and carers: Local authorities e.g. Hampshire County Council and NHS Hampshire Hospitals, drew on Wolke's research to increase parents', carers' and teachers' understanding of how premature children are affected in their development and learning **[5.10]**. Neonatal societies e.g. Royal College of Occupational Therapists, used his work in practice guidelines (2017) to raise awareness for occupational therapists about how preterm children remain at high risk for neurodevelopmental disability compared with term peers **[5.11]**.

Department for Education (DfE) guidelines: DfE's *Advice on the admission of summer born children for local authorities and school admission authorities and parents* (July 2013, revised September 2020 as *Summer Born Children Starting School: Advice for parents*) used Wolke's research as part of the evidence base to *"…take account of the age group the child would have fallen into if born on time."* **[5.12a; 5.12b]**. This guidance from DfE details the framework that UK school authorities must operate under and takes account of the needs of 12,000 parents of preterm children per year who are able to request a delayed enrolment date (around 15% of all requests) **[5.12c]**.

5. Sources to corroborate the impact (indicative maximum of 10 references)

[5.1] EFCNI Standards of Care - https://newborn-health-standards.org/project/downloads/, and Standards of Care toolkit - https://newborn-health-standards.org/wp-content/uploads/2019/09/ESCNH_Toolkit.pdf
[5.2] Statement from the chair of the EFCNI.
[5.3] National Institute for Health and Care Excellence (2017). *Developmental follow-up of children and young people born preterm*. (NICE Guideline 72), https://tinyurl.com/yysmyjej
[5.4] International Consortium for Health Outcome Measurement (ICHOM) (2020) *Preterm and Hospitalized Newborn Health: Standard Set*. https://tinyurl.com/y4bpsee8
[5.5] The British Association of Neonatal Neurodevelopmental Follow up (March 2020) Guidance for telephone–video clinics during the Covid-19 pandemic. [PDF available on file]
[5.6] Confirmation of use and benefits of PARCA-R during covid-19: statements from **(a)** Swiss Society of Neonatology and **(b)** the National Maternity Hospital, Dublin.
[5.7] PARCA-R website, https://www2.le.ac.uk/partnership/parca-r. [Download data available on file]
[5.8] Statement from Consultant Neonatologist, Royal Hospital for Children, Glasgow.
[5.9]. Swedish Neonatal Society: *national guidelines for the development of neonatal at-risk children* (2015, in Swedish), [Nationella-Uppfoljningsprogrammet] https://tinyurl.com/1ks3nnws
[5.10] Hampshire County Council and NHS Hampshire Hospitals (2017). *Development and learning of children who have been born prematurely: Information for parents, carers and educational professionals* [available on file]
[5.11] Royal College of Occupational Therapists practice guidelines: *Occupational therapy in neonatal services and early intervention* (2017), https://tinyurl.com/yxbbvn3p
[5.12] Department for Education: **(a)** *Advice on the admission of summer born children, 2013,* https://tinyurl.com/y4ndq4s6; **(b)** *Summer Born Children Starting School: Advice for parents (2020),* https://tinyurl.com/y5kqzrqe*;* **(c)** *Delayed school admissions for summer born pupils, research report (2018),* https://tinyurl.com/y6p9tu8t