

ranged from 11%-61%; no guideline was deemed suitable for use. Only Swiss and Canadian guidelines were considered useable with significant modifications.

Conclusion Several international guidelines on perinatal care of 22–25 wk GA infants exist. Using the AGREE-II tool, we identified many deficits in the quality of these guidelines. Not a single guideline was deemed suitable for use using the AGREE-II tool. Use of poorly developed guidelines may be detrimental to decision-making, thus there is a need for transparent and rigorous guidelines regarding the perinatal care of 22–25 wk GA infants.

PS-050 QUALITY OF LIFE FOR PARENTS OF VERY-LOW BIRTH WEIGHT INFANTS ENROLLED IN A CLINICAL STUDY

¹T Nordheim, ²T Rustoen, ¹B Nakstad. ¹Department of Children and Adolescents Medicine, Akershus University Hospital, Lørenskog, Norway; ²Acute Clinic, Oslo University Hospital, Oslo, Norway

10.1136/archdischild-2014-307384.347

Background In this study we wanted to evaluate if parents of very-low birth weight (VLBW) infants enrolled in a clinical study developed a lower quality of life compared to parents from a control sample.

Methods We recruited parents of children attending the Norwegian multicenter study for premature nutrition (PreNu). The PreNu study was a randomised clinical nutritional trial, where 50 VLBW-children (<1500 g) were recruited within the first hours of their life. We also recruited parents of VLBW-children born immediately before and after the recruitment period of the PreNu study, to serve as a control group.

The parents (n = 63) were given a questionnaire with validated measures on quality of life (Quality of Life Scale), anxiety and depression (Hospital Anxiety and Depression Scale), fatigue (Lee Fatigue Scale), sleeping disturbance (General Sleep Disturbance Scale), pain (Brief Pain Inventory), comorbidity (Self-Administered Comorbidity Questionnaire) and hope (Herth Hope Index). The parents were asked to answer as they would have done at the time their children were at the NICU.

Results The response rate was 69%. T-tests showed no significant difference between the groups on all measures except for quality of life. The PreNu parents rated their quality of life significantly higher than the control group (p = 0.018).

Conclusion Our fear that the parents of the PreNu-children suffered an intolerable burden seems unfounded. The results suggest that being the parent of a VLBW-child attending a clinical study is not a burden, but may in fact be an enrichment.

PS-051 RANDOMISED CONTROLLED TRIALS IN VERY PRETERM INFANTS: DOES INCLUSION IN THE STUDY RESULT IN ANY LONG-TERM BENEFIT?

¹CM Rüegger, ²A Kraus, ¹B Koller, ³G Natalucci, ³B Latal, ¹E Waldesbühl, ¹JC Fauchère, ²L Held, ¹HU Bucher. ¹Division of Neonatology, University Hospital Zurich, Zurich, Switzerland; ²Division of Biostatistics, University of Zurich, Zurich, Switzerland; ³Child Development Center, University Children's Hospital, Zurich, Switzerland

10.1136/archdischild-2014-307384.348

Background Since the introduction of randomised controlled trials (RCT) in clinical research, there has been discussion of whether enrolled patients have worse or better outcomes than comparable nonparticipants.

Objective To investigate whether very preterm infants randomised to a placebo group in a RCT have equivalent neurodevelopmental outcomes to infants who were eligible but not randomised (eligible NR).

Methods In the course of an RCT investigating the neuroprotective effect of early high dose erythropoietin on the neurodevelopment of very preterm infants, the outcome data of 72 infants randomised to placebo were compared with those of 108 eligible NR infants. Our primary outcome measures were the mental (MDI) and psychomotor (PDI) developmental indices of the Bayley Scales of Infant Development II at 24 months corrected age. The outcomes of the two groups were considered equivalent if the confidence intervals of their mean differences fitted within our ± 5 point margin of equivalence.

Results Except for a higher socioeconomic status of the trial participants, both groups were balanced for most perinatal variables. The mean difference (90% CI) between the placebo and the eligible NR group was -2.1 (-6.1 and 1.9) points for the MDI and -0.8 (-4.2 and 2.5) points for the PDI (in favour of the placebo group). After adjusting for the socioeconomic status, maternal age and child age at follow-up, the mean difference for the MDI was -0.5 (-4.3 and 3.4) points.

Conclusions Our results indicate that the participation of very preterm infants in an RCT is associated with equivalent long-term outcomes compared to non-participating infants.

PS-052 SETTING PRETERM BIRTH RESEARCH PRIORITIES WITH MULTIPLE PROFESSIONS AND SERVICE USERS IN THE UK

¹S Uhm, ²F Alderdice, ³I Brady, ¹B Chambers, ⁴Z Chivers, ⁵S Crowe, ⁶AL David, ⁷S Deshpande, ⁸C Gale, ⁹G Gyte, ⁶CP James, ¹⁰L Duley, ¹¹J McNeill, ¹²A Shennan, ¹³MA Turner, ¹S Oliver. ¹Institute of Education, University of London, London, UK; ²The Premature Baby Charity for Northern Ireland, TinyLife, Carryduff, UK; ³Irish Premature Baby, Irish Premature Baby, Dublin, Ireland; ⁴The Premature and Special Care Baby Charity, Bliss, London, UK; ⁵James Lind Alliance, James Lind Alliance, London, UK; ⁶University College London, Institute for Women's Health, London, UK; ⁷British Association of Perinatal Medicine, British Association of Perinatal Medicine, London, UK; ⁸Academic Neonatal Medicine, Imperial College, London, UK; ⁹National Childbirth Trust, National Childbirth Trust, London, UK; ¹⁰University of Nottingham, Nottingham Clinical Trials Unit, Nottingham, UK; ¹¹The Premature Baby Charity for Northern Ireland, TinyLife, Carryduff, UK; ¹²Kings College London, Kings College London, London, UK; ¹³Liverpool Women's NHS Foundation Trust, Liverpool Women's NHS Foundation Trust, Liverpool, UK

10.1136/archdischild-2014-307384.349

Background Preterm birth is the most important determinant of adverse infant outcomes. Research agendas in this area have been determined primarily by researchers.

Objectives To identify and prioritise future research areas in preterm birth that are most important to service users and practitioners.

Methods A priority setting partnership was established with families with experience of preterm birth and organisations representing them, obstetricians, neonatologists, midwives and neonatal nurses. Research uncertainties were gathered from surveys and analysis of systematic reviews and clinical guidance. Prioritisation was through voting; final ranking occurred at a facilitated workshop, as advocated by the James Lind Alliance.

Results 593 uncertainties were submitted by 386 respondents (58% service users, 30% healthcare professionals and 12% from those in both roles); 52 were identified from literature