

REGULAR ARTICLE

# Spanish survey on follow-up programmes for children born very preterm

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## Keywords

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## ABSTRACT

**Aim:** To describe variations in practice between follow-up programmes for very preterm children born at less than 32 weeks' gestation or with very low birth weight of less than 1,500 g.

**Methods:** A survey on follow-up practices was electronically distributed to level II and III units among hospitals of the Spanish National Health Service in 2016. The survey included 70 questions covering issues such as follow-up organisation and resources, routine assessments, relationships with other services and families, information management and training.

**Results:** The response rate was 91.5% (141/154). Among respondents, 70.9% (100/141) reported that they do provide follow-up and 42% do so up to six years of age. Routine neurological and ophthalmological follow-up is not performed in 60% and 37% of hospitals, respectively, and a second hearing assessment is not given in 62%. Just 38% of units have psychologist. In 41% of hospitals, training in follow-up skills is not included in Paediatric Residency training programme.

**Conclusion:** Although Spain has a nationwide health system that provides universal health coverage, we found that follow-up care for children born very preterm/very low birth weight is not equitable. Nearly half of paediatric residents receive no training in follow-up for this high-risk population.

## INTRODUCTION

For children born very preterm (VPT) at less than 32 weeks of gestation or born with very low birth weight (VLBW) of less than 1,500 g, follow-up programmes are essential to provide necessary ongoing care after hospital discharge for these children and their families. This becomes even more relevant with the progressive improvement in survival, which conditions that more children unequivocally require highly specialised care. Additionally, the information collected during the follow-up of VPT/VLBW children facilitates the evaluation of clinical practice in neonatal intensive care units (NICUs) and assessment of the efficacy and/or downsides of interventions performed during hospital admission that require follow-up to some extent (1).

The benefits of follow-up programmes have been well established (2,3). Nevertheless, information is very limited regarding how the content and timing of activities performed in specialised clinics should be structured, what assessments should be performed, which specialists should

## Abbreviations

NICUs, Neonatal intensive care units; VPT/VLBW, Very preterm children born at less than 32 weeks of gestation or born with very low birth weight of less than 1,500 g.

## Key notes

- We present an overall picture of heterogeneity in follow-up programmes for children born very preterm at level II-III neonatal intensive care units (NICUs) of the Spanish National Health System.
- Despite having a nationwide health system with universal coverage, NICU follow-up programmes differ considerably among centres in Spain.
- Training of professionals and participation of specialists, such as psychologists, are the main barriers to increasing the quality of follow-up care for this high-risk population.

intervene, and even the duration of follow-up programmes (1,4–6). Moreover, little information is available on how follow-up programmes should be coordinated with primary care or early intervention health and social care providers. General recommendations have been published for the follow-up of high-risk infants (7) and, more recently, of preterm children (8); however, the necessary degree of implementation of such follow-up is unknown. Three North American surveys (9–11) on follow-up of high-risk children (not specifically VPT/VLBW children) have provided useful information about the practices implemented in follow-up programmes, but these surveys mainly focused on the availability of resources for such programmes (10,11).

The National Health System in Spain has achieved near-universal health coverage and therefore should provide the entire population with equal resources; more specifically, the health system should provide ongoing care and assessment of VPT/VLBW children via follow-up programmes. Until recently, Spain lacked specific national follow-up guidelines for clinical practice. However, in 2017 the Spanish Neonatal Society, together with the Spanish Association of Primary Health Care Paediatrics, issued a detailed guidance document on the follow-up of VPT/VLBW children (12). As part of the guidance development process, we launched a national survey to retrieve updated information regarding the characteristics of follow-up programmes for VPT/VLBW in level II and level III NICUs in Spain. We hypothesised that the content of follow-up care received by VPT/VLBW children would differ considerably as a function of the characteristics of the follow-up programme and level of the neonatal unit. The primary objective of the present study was to describe the variations in practice among follow-up programmes in Spain. In addition, we aimed to assess the level of implementation of a recently developed set of recommendations and identify the perceived needs of staff involved in follow-up programmes.

## METHODS

### Study design

This study was a cross-sectional survey performed from April 2016 to November 2016. Eligible participants were NICUs classified as level II and level III according to the recommendations of the Spanish Neonatal Society (13) and pertaining to the National Health System network of the Spanish Ministry of Health. These hospitals are responsible for care in approximately 80% of the total births in Spain. The information requested referred to data collected in 2015.

Survey procedures and the questionnaire were designed by the Follow-Up Committee of the Spanish Neonatal Society and included both neonatologists and primary care paediatricians. The survey protocol was submitted to the Research Ethics Committee of University Hospital 12 de Octubre, but evaluation was deemed not to be required.

The survey questionnaire included 70 closed-ended questions and covered areas such as structural organisation, resources, evaluation calendars and flow charts, training,

involvement of specialists and primary care paediatricians, as well as early intervention services, and associations for the parents of premature children. Most questions referred to routine follow-up visits, such as clinical visits performed for all children regardless of their health status. A set of questions aimed at obtaining baseline practice data on clinical assessments included in the recommendations (12) were developed by the same panel that designed the survey, prior to the publication and dissemination of the guidance document. At the end of the questionnaire, respondents were asked to select and rank, from an 8-item list, the main perceived needs related with setting-up and running a follow-up programme for VPT/VLBW children.

An invitation to participate and to complete the encrypted online questionnaire was sent electronically to directors and follow-up teams of level II and III NICUs in Spain. The survey was accessible for eight months through a web platform. Five reminders were emailed at intervals of 15, 30 and 60 days. All investigators were committed to protect data confidentiality and to not use NICU identifying information in any presentation of the survey results.

### Data analysis

Absolute and relative frequencies were calculated for the different response categories of each item. Total and individual responses were presented in tables. Chi-square tests were performed to compare the response proportions by unit level. *p* values <0.05 were considered significant. The 8-item ranking was summarised as the proportions of responses for the top three ranked items.

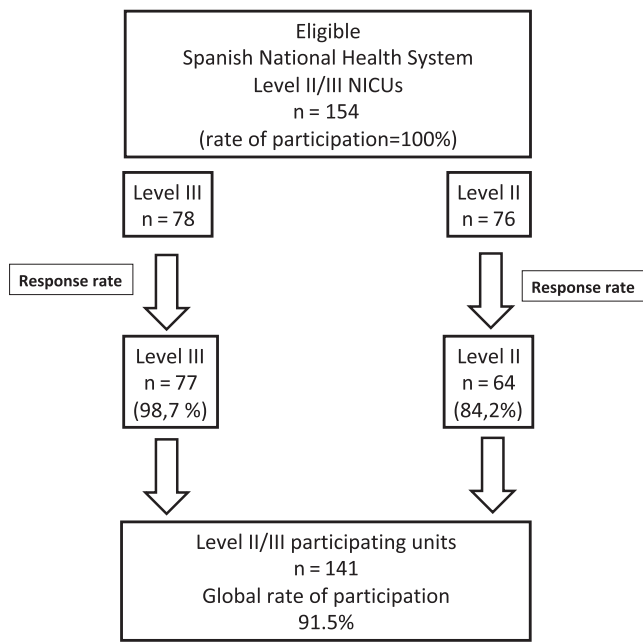
## RESULTS

We contacted all 154 neonatal units in public hospitals registered with the Spanish Ministry of Health, and 141 (91.5%) completed the questionnaire. Figure 1 shows percentage of responses according to level of care. In 2015, 20% of units (28/141) had fewer than 1,000 deliveries, 62% (87/141) had between 1,000 and 2,999 and 18% (26/141) attended more than 3,000 deliveries.

Table 1 shows VPT/VLBW admissions by level of care. Among responding NICUs, 70.9% (100/141) reported running a follow-up clinic for VPT/VLBW children, with a higher proportion among level III units (76/77, 98.7%) than among level II (24/64, 37.5%) units (*p* < 0.001). All neonatal units running a follow-up clinic (*n* = 100) fully completed the questionnaire.

Table 2 summarises survey results relating to follow-up clinic organisation and resources as well as routine assessments. Table 3 details how follow-up clinics are related to other services and manage information, training of all healthcare professionals involved in the clinics, and losses to follow-up. A summary of the degree to which practice is in line with the recently developed recommendations is presented in Table 4.

In the 8-item ranking, respondents listed the three main priorities for increasing the quality of follow-up programmes. The most important aspect was to improve



**Figure 1** Flow diagram of public hospitals participating in this study, the level of care provided in their neonatal units, and the survey response rate.

training of the healthcare professionals running the clinics; two-thirds of respondents considered this to be the most important need, and 82% considered it one of the top three priorities. The second priority was inclusion of a full-time psychologist on the follow-up team. Finally, the third priority was to develop a national follow-up protocol, with 50% of respondents ranking this among the top three priorities.

## DISCUSSION

The results of a national survey analysing the characteristics of follow-up programmes for VPT/VLBW children in Spain conducted during 2015 showed great heterogeneity in programme content, both between and within different neonatal levels of care. Remarkably, none of the follow-up programmes fulfilled the recommendations regarding routine assessment by a paediatric specialist (such as an

ophthalmologist or neurologist), included in the recently developed guidance document of the Spanish Neonatal Society (12). For clinicians running follow-up programmes, the main perceived need was related to training.

Among the strengths of this survey was the high response rate (91.5%), which indicates that the results are representative of follow-up practices in Spain. We are unaware of another equally detailed survey on follow-up practices for very premature children having been conducted in other European countries. The limitations of this survey were mainly those inherent to all practice surveys regarding accuracy of the responses and appropriateness of the respondents. The survey results considered only the information reported, and no validation study was performed to check whether the responses matched the actual practice.

When the survey was conducted, guidance on standardised follow-up care was unavailable and no minimum requirements had been established. The survey incorporated a series of specific questions about clinical assessments that were recommended in a recently issued Spanish national protocol (12). The degree of compliance with the recommended assessments was very low; in fact, no single centre met all recommendations. This can be attributed to a lack of resources in some cases, but we believe that it also is influenced by a lack of familiarity with how follow-up clinics should be organised.

Both neonatal and paediatric scientific societies and other organisations recommend the monitoring of high-risk children (8,13,14), including those born VPT/VLBW. Despite these recommendations, there is very little information on what assessments should be performed as part of a standard protocol (6,10,14,15), which may at least partly explain the lack of homogeneity observed in the follow-up care received by children born very premature. In fact, the lack of guidelines or recommendations has been identified in workshops focusing on follow-up care (5,6) as one of the most important barriers to providing adequate care. A study conducted in California showed that nearly 20% of very low birth weight children were never referred for high-risk follow-up (16). A very recent editorial letter informed that only 64% of units in the United Kingdom (UK) have a dedicated neurodevelopmental follow-up service for high-risk neonates (17). In addition, considering that up to 30% of children stop attending follow-up appointments (18),

**Table 1** Number of infants born weighing less than 1,500 g, admitted annually to participating Spanish hospitals

| Participating units | Number of infants born weighing <1,500 g |            |          |            |          |
|---------------------|--|------------|----------|------------|----------|
|                     | 0  | 1–20       | 21–50    | 51–100     | >101     |
| Level II<br>n = 64  | 35 (54.6%)                               | 28 (43.7%) | 1 (2.1%) | 0 (0%)     | 0 (0%)   |
| Level III<br>n = 77 | 0 (0%)                                   | 14 (18.2%) | 37 (48%) | 20 (26%)   | 6 (7.8%) |
| Total<br>n = 141    | 35 (24.8%)                               | 42 (29.7%) | 38 (27%) | 20 (14.2%) | 6 (4.2%) |

**Table 2** Organisation of routine clinic and assessments, overall and by level of care

|   | Total (n = 100)<br>n (%) | Level III (n = 76)<br>n (%) | Level II (n = 24)<br>n (%) | p      |
|---|--------------------------|-----------------------------|----------------------------|--------|
| <b>Organisation and resources</b>   |                          |                             |                            |        |
| There is a follow-up clinic more than 2 days a week.  | 37 (37)                  | 35 (46)                     | 2 (8.3)                    | 0.000  |
| More than 20 minutes are available for each child.  | 76 (76)                  | 59 (77.6)                   | 17 (70.8)                  | ns     |
| There are one or more doctors dedicated exclusively to follow-up.                             | 48 (48)                  | 37 (48.7)                   | 11 (45.8)                  | ns     |
| The doctor in charge of the clinic is a neonatologist.  | 80 (80)                  | 67 (88.2)                   | 13 (54.2)                  | 0.000  |
| Follow-up is only conducted until 2 years of age.   | 22 (22)                  | 11 (14.5)                   | 11 (45.8)                  | 0.001  |
| Follow-up is conducted until at least 6 years of age.   | 42 (42)                  | 34 (44.7)                   | 8 (33.3)                   | ns     |
| Child health check-ups during the first year are conducted every 3 months.                    | 78 (78)                  | 59 (77.6)                   | 19 (79.2)                  | ns     |
| Reviews during the second year are held every 6 months.                                       | 84 (84)                  | 68 (89.5)                   | 16 (66.7)                  | 0.003  |
| Child health check-ups after the second year are conducted annually.                          | 71 (91)                  | 60 (92.3)                   | 11 (84.6)                  | ns     |
| All infants born at 32–36 weeks' gestation who had an inpatient stay are also followed up.    | 41 (41)                  | 26 (34.2)                   | 15 (62.5)                  | 0.01   |
| A specific programme is available for infants born at 32–36 weeks' gestation.                 | 40 (40)                  | 24 (31.6)                   | 16 (66.7)                  | 0.002  |
| There is a written protocol for the follow-up of children who were VPT/VLBW at birth.         | 73 (73)                  | 59 (77.6)                   | 14 (58.3)                  | ns     |
| Children's electronic medical records can be consulted by both the hospital and primary care. | 66 (66)                  | 49 (64.5)                   | 17 (70.8)                  | ns     |
| A psychologist is available to assist during follow-up.                                       | 38 (38)                  | 33 (43.4)                   | 5 (20.8)                   | 0.05   |
| The psychologist involved in follow-up is a member of hospital staff.                         | 12 (12)                  | 11 (14.5)                   | 1 (4.1)                    | ns     |
| There is a multidisciplinary team available for the care of children with cerebral palsy.     | 57 (57)                  | 53 (69.7)                   | 4 (16.7)                   | <0.001 |
| <b>Routine assessments</b>  |                          |                             |                            |        |
| A neurologist routinely assesses all children (NO).   | 60 (60)                  | 45 (59.2)                   | 15 (62.5)                  | ns     |
| A neurologist assesses the child four or more times during follow-up.                         | 27 (27)                  | 20 (26.3)                   | 7 (29.1)                   | ns     |
| An ophthalmologist routinely assesses all children (NO).                                      | 37 (37)                  | 29 (28.1)                   | 8 (33.3)                   | ns     |
| An ophthalmologist assesses the child four or more times during follow-up.                    | 21 (21)                  | 13 (17.1)                   | 8 (33.3)                   | ns     |
| Hearing assessment is routinely performed on all children (NO)                                | 62 (62)                  | 43 (56.5)                   | 19 (79.1)                  | 0.05   |
| The Denver or Haizea-Llevant scales are used.   | 66 (66)                  | 51 (67.1)                   | 15 (62.5)                  | ns     |
| The Bayley II or III test is used.  | 24 (24)                  | 22 (28.9)                   | 2 (8.3)                    | 0.04   |
| Other development scale (apart from the Bayley scales) is used.                               | 15 (19.7)                | 15 (27.7)                   | 0 (0)                      | 0.006  |
| The M-CHAT is administered.   | 18 (18)                  | 15 (19.7)                   | 3 (12.5)                   | 0.04   |
| The child is screened for attention deficit hyperactivity disorder.                           | 16 (16)                  | 15 (19.7)                   | 1 (4.1)                    | 0.04   |

M-CHAT, Modified Checklist for Autism in Toddlers; ns, not significant; VPT/VLBW, very preterm/very low birth weight.

**Table 3** Clinical relationships, information management, training, and losses to follow-up, overall and by level of care

|  | Total (n = 100)<br>n (%) | Level III (n = 76)<br>n (%) | Level II (n = 24)<br>n (%) | p     |
|--|--------------------------|-----------------------------|----------------------------|-------|
| <b>Relationships with the follow-up clinic</b>   |                          |                             |                            |       |
| There is standardised contact with primary care  | 28 (28)                  | 21 (27.6)                   | 7 (29.2)                   | ns    |
| The follow-up clinic is coordinated with primary care  | 26 (26)                  | 19 (25)                     | 7 (29.2)                   | ns    |
| There are established meetings with early intervention services  | 50 (50)                  | 40 (52.6)                   | 10 (41.7)                  | ns    |
| A new assessment must be completed to access early intervention services   | 58 (58)                  | 43 (56.6)                   | 15 (62.5)                  | ns    |
| Children begin early intervention services before 3 months after discharge (NO)  | 29 (29)                  | 21 (27.6)                   | 8 (33.3)                   | ns    |
| There are relationships with associations for parents of premature children  | 29 (29)                  | 31 (40.8)                   | 4 (16.6)                   | 0.03  |
| Strengthening of relationships with associations for parents of premature children is viewed positively                  | 85 (85)                  | 64 (84.2)                   | 21 (87.5)                  | ns    |
| <b>Information management</b>  |                          |                             |                            |       |
| Follow-up information is recorded in a database  | 47 (47)                  | 42 (55.3)                   | 5 (20.8)                   | 0.003 |
| The data are reviewed to assess children's progress  | 50 (50)                  | 45 (59.2)                   | 5 (20.8)                   | 0.001 |
| The data are reviewed to compare the results with those of other units   | 35 (35)                  | 33 (43.4)                   | 2 (8.3)                    | 0.02  |
| <b>Training</b>  |                          |                             |                            |       |
| Specific training on follow-up has been received (NO)  | 19 (19)                  | 14 (18.4)                   | 5 (20.8)                   | ns    |
| Paediatric residents gain experience in the follow-up clinic during their training (NO)                                  | 41 (41)                  | 29 (38.2)                   | 12 (50)                    | ns    |
| It is considered that staff have sufficient knowledge to advise parents on treatment of a child with cerebral palsy (NO) | 74 (74)                  | 52 (68.4)                   | 22 (91.7)                  | 0.02  |
| <b>Loss to follow-up</b>   |                          |                             |                            |       |
| Less than 10% lost to follow-up.   | 45 (45)                  | 29 (38.1)                   | 16 (66.6)                  | 0.01  |

ns, not significant.

**Table 4** Compliance with the recommendations of the new Spanish national protocol before its dissemination

|  | Total (n = 100)<br>n (%) | Level III (n = 76)<br>n (%) | Level II (n = 24)<br>n (%) | p     |
|--|--------------------------|-----------------------------|----------------------------|-------|
| Alignment of practice with new recommendations   |                          |                             |                            |       |
| 1. The first assessment by a paediatric neurologist is done before 1 year of corrected age.    | 38 (38)                  | 29 (38.1)                   | 9 (37.5)                   | ns    |
| 2. Assessment of the visual abnormalities is made by an ophthalmologist before 3 years of age. | 54 (54)                  | 38 (50)                     | 16 (66.7)                  | ns    |
| 3. The child's hearing is assessed between 18 and 30 months of age.                            | 14 (14)                  | 13.5 (56.6)                 | 16.6 (62.5)                | ns    |
| 4. The Bayley or another similar scales are administered between 18 and 30 months of age.      | 25 (25)                  | 24 (31.6)                   | 1 (4.2)                    | 0.006 |
| 5. The M-CHAT questionnaire is administered.   | 18 (18)                  | 15 (19.7)                   | 3 (12.5)                   | 0.04  |
| Compliance with the five recommendations   |                          |                             |                            |       |
| Units that do not meet any of the recommendations.   | 22 (22)                  | 16 (21)                     | 6 (25)                     |       |
| Units that meet one of the recommendations.  | 34 (34)                  | 25 (32.8)                   | 9 (37.5)                   |       |
| Units that meet two of the recommendations.  | 22 (22)                  | 19 (25)                     | 3 (12.5)                   |       |
| Units that meet three of the recommendations.  | 16 (16)                  | 10 (13.1)                   | 6 (25)                     |       |
| Units that meet four of the recommendations.   | 6 (6)                    | 6 (7.8)                     | 0 (0)                      |       |
| Units that meet all five recommendations.  | 0 (0)                    | 0 (0)                       | 0 (0)                      |       |

M-CHAT, Modified Checklist for Autism in Toddlers; ns, not significant.

nearly half of those weighing less than 1,500 g at birth will not receive specialised follow-up. However, almost half of hospitals participating in the survey reported a loss to follow-up of less than 10%.

Surveys on the follow-up practices identified by the authors have been conducted in the United States (US) and Canada (9–11), and these have referred globally to high-risk children and not specifically to children born VPT/VLBW, who constitute a very specific group within the overall population of high-risk children. There is a striking lack of specific information on follow-up programmes for children born weighing less than 1,500 g. This paediatric population does stand out as a well-differentiated group when results of follow-up are analysed; nevertheless, this group is included in the global population of at-risk children when discussing follow-up programmes. Further, it may be easier to establish specific recommendations for VPT/VLBW children, as they tend to have similar needs.

Coinciding with our survey, a study carried out by Bockli et al. (11) in the United States identified neonatologists as the main specialists responsible for follow-up in most centres. Follow-up was continued beyond five years in only 26% of public hospitals and 9% of private hospitals; in Spain, we found that 42% of hospitals offered longer follow-up, a finding that we consider very positive. Bockli et al. (11) concluded that the assessments and services provided by follow-up units in the United States were quite similar, but the authors analysed the programmes from a general point of view. In contrast, the Canadian survey (9) identified great variability in practice, which correlates perfectly with our findings.

From our results, it should be highlighted that only a few hospitals had a staff psychologist and almost a third of the units reported that children had access to early intervention services not before three months after discharge. Early intervention has been shown to improve progress in both

the motor and psychological development of these children; therefore, it should be a priority for families to have access to early intervention services immediately after discharge (19,20). Emotional, behavioural and relational disorders among very premature children (21–23) are being recognised as increasingly important; hence, integration of a psychologist into follow-up programme teams becomes indispensable for conducting assessments and guiding families through the process of accessing resources available for treatment.

The relationship between follow-up programmes and primary care has not been well established. Hospital-based staff who run follow-up clinics should routinely establish contact with primary care paediatricians and include them as part of their programmes. This would offer an important set of benefits for the child and the family. Primary care physicians would have updated information and, as a consequence, duplication of tests and hospital appointments could be avoided. Moreover, the family doctor would also gain the families' confidence throughout the entire process. In this regard, sharing clinical records between hospitals and primary care physicians would greatly facilitate the task. At the time when our survey was performed, approximately two-thirds of the units surveyed were able to share electronic medical records with primary care paediatricians.

In this survey, only 30% of units collaborated with associations of parents of premature children in relation to follow-up of the children. Undoubtedly, the involvement of parents' associations plays a key role in providing information, resources and social support to families that face a similar problematic situation.

One of the most striking problems revealed by our survey is the insufficient amount of specific training in follow-up received by healthcare professionals devoted to the care of neonates. This was confirmed in the responses to both specific questions and the ranking part of the survey. Among

the different options proposed to improve the quality of follow-up programmes, improvement of specific coaching during residency training was unequivocally identified as an urgent priority. In some countries, such as the United States, development of a follow-up programme is a prerequisite for a centre to receive accreditation to train specialists in neonatology (7). In addition, when considering more specific issues such as cerebral palsy, 75% of professionals did not consider themselves sufficiently qualified to provide advice regarding treatment. Professionals from the UK have the same perception about the availability of appropriately trained staff (17). Following the publication of the national follow-up protocol in Spain (12), it seems undeniable that the Spanish Neonatal Society should include changes to its Syllabus Requirements for Paediatricians, for physicians to acquire specific accreditation as a neonatologist.

Despite the recommendation of the Spanish Neonatal Society (13) that level II hospitals should not care for VPT/VLBW, some regional health authorities do not treat this recommendation as mandatory; therefore, some level II centres continue to attend children VPT/VLBW. This is clearly an area for improvement in the care of VPT/VLBW children in Spain. Regionalisation of care at the appropriate care level is an evidence-based practice that yields decreased mortality and morbidity (24).

The present study shows how the practices carried out in follow-up clinics and their organisation are markedly heterogeneous and that for this reason, VPT/VLBW children in Spain are not receiving equitable care, despite the universality of the Spanish public health system. We expect that dissemination of the national protocol (12), enhancement of regionalisation, generalisation of the presence of a psychologist on follow-up teams, and improvement in the training of professionals, will together not only standardise practice but will significantly increase the quality of survival and neurodevelopment of preterm infants. Therefore, we plan to conduct a new survey in the near future to determine whether implementation of the suggested areas for improvement has resulted in improved conditions in the care of VPT/VLBW children in Spain.

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#### CONFLICTS OF INTEREST

The authors have no conflicts of interest relevant to this article to disclose.

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