**Table 2.** Thresholds for complex or elevated care needs used in the published literatureand for the EPICE cohort

|  |  |
| --- | --- |
| **Complex or elevated care in published literature** | **Elevated care definitions for the EPICE cohort** |
| **Bramlett et al. (2009)**  *Children with special care needs aged 0*–*17 years, visits during past year:*  ≥3 doctor’s visits for sick care, or  ≥2 emergency room visits, or  ≥1 specialist visit  *(Specialty doctor, physical, occupational or speech therapy, mental health care or counselling or home health care)*  More visits indicate an increased level of complexity  **Kuo et al. (2014)**  Multiple needs across different domains  ≥2 specialists consulted in the previous year  *(Specialty doctor, physical, occupational or speech therapy, mental health care or counselling or home health care)*  **Brenner et al. (2018)**  Multidimensional care that manages multiple condition-related needs  **Patra and Greene (2017)**  *Children born very preterm, visits from discharge until 22 months:*  ≥2 hospitalizations, or  ≥2 emergency room visits, or  Follow-up by ≥2 medical pediatric specialist  *(Excluding therapies such as developmental, speech and physical therapy)* | **Elevated outpatient/inpatient service use**  *During the past year*  ≥4 doctor’s visits for sick-care in total including visits to general practitioner, pediatrician, nurse and/or school nurse, or  ≥3 emergency room visits, or  ≥1 overnight hospitalization  **Elevated specialist service use**  *During the past year*  ≥2 different specialistsor  ≥3 visits to same specialist from the following list:  Neurologist  Ear-nose-throat, hearing or ear specialist  Ophthalmologist or eye specialist  Speech therapist  Psychologist  Psychiatrist  Physiotherapist or psychomotor therapist  Respiratory, asthma, lung or allergy specialist  Dietitian or nutritionist  Occupational therapist  Early intervention services  Multidisciplinary services |

**Table 3.** Health-care services used during the past year at five years of age in children born very preterm (excluding routine check-ups and vaccinations)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Health-care service** | **Total** | **No, occasional, frequent visits\*** | | | **Number of visits** | |
| **Outpatient services** | N | % no visit | % 1-3 visits | % 4 or more | Mean (SD) | Median [IQR] |
| General practitioner (because of illness) | 3537 | 45.3 | 38.3 | 16.4 | 2.0 (3.9) | 1 [0-3] |
| Pediatrician (because of illness) | 3537 | 47.5 | 36.0 | 16.5 | 2.0 (4.7) | 1 [0-2] |
| Nurse | 3537 | 96.6 | 2.4 | 1.0 | 0.2 (4.4) | 0 [0-0] |
| School nurse | 3537 | 90.6 | 8.5 | 0.9 | 0.2 (1.5) | 0 [0-0] |
| Total number of visits to providers above | 3537 | 15.7 | 46.3 | 38.0 | 4.3 (8.2) | 3 [1-5] |
|  | N | % no visit | % 1-2 visits | % 3 or more | Mean (SD) | Median [IQR] |
| Emergency room | 3537 | 69.9 | 24.7 | 5.4 | 0.6 (1.5) | 0 [0-1] |
| **Inpatient services** | N | % no hospitalization | % 1 hospitalization | 2 or more | Mean (SD) | Median [IQR] |
| Hospitalized over night | 3527 | 88.8 | 9.5 | 1.8 | 0.1 (0.4) | 0 [0-0] |
| **Outpatient and inpatient** | N | % no visit | % 1-3 visits | % 4 or more | Mean (SD) | Median [IQR] |
| Total number of visits, outpatient and inpatient | 3586 | 13.9 | 41.9 | 44.2 | 4.9 (8.7) | 3 [1-6] |
| **Specialist services** | N | % no visit | % 1-2 visits | % 3 or more | Mean (SD) | Median [IQR] |
| Neurologist | 3537 | 90.3 | 7.8 | 1.9 | 0.2 (2.4) | 0 [0-0] |
| Ear-nose-throat or hearing specialist | 3537 | 70.6 | 22.1 | 7.2 | 0.6 (1.7) | 0 [0-1] |
| Ophthalmologist or eye specialist | 3537 | 58.2 | 32.6 | 9.2 | 1.0 (3.0) | 0 [0-1] |
| Speech therapist | 3537 | 76.4 | 6.5 | 17.2 | 6.3 (20.9) | 0 [0-0] |
| Psychologist | 3537 | 89.4 | 6.4 | 4.2 | 1.0 (7.7) | 0 [0-0] |
| Psychiatrist | 3537 | 96.2 | 2.9 | 0.9 | 0.1 (2.0) | 0 [0-0] |
| Physiotherapist | 3537 | 84.4 | 4.0 | 11.6 | 6.0 (23.5) | 0 [0-0] |
| Respiratory or lung specialist or allergologist | 3537 | 89.3 | 8.2 | 2.5 | 0.3 (3.9) | 0 [0-0] |
| Dietitian or nutritionist | 3537 | 95.5 | 2.6 | 1.9 | 0.1 (0.8) | 0 [0-0] |
| Occupational therapist | 3537 | 92.2 | 2.1 | 5.8 | 2.3 (12.5) | 0 [0-0] |
| Early intervention service | 3537 | 93.5 | 2.2 | 4.3 | 1.4 (10.1) | 0 [0-0] |
| Multidisciplinary service\*\* | 3537 | 96.3 | 3.3 | 0.5 | 2.7 (10.6) | 1 [1-1] |
| Total number of visits to specialists | 3537 | 30.5 | 26.1 | 43.4 | 19.3 (52.8) | 2 [0-8] |
|  | N | % no specialist | % 1 specialist | % 2 or more | Mean (SD) | Median [IQR] |
| Number of different specialists seen | 3537 | 30.5 | 28.8 | 40.7 | 1.7 (1.8) | 1 [0-2] |
| **All services** | N | % no visit | % 1-3 visits | % 4 or more | Mean (SD) | Median [IQR] |
| Total number of visits, all services included | 3586 | 7.4 | 25.4 | 67.2 | 23.9 (55.2) | 6 [3-15] |

All proportions, means (SD) and medians [IQR] are weighted with inverse probability weights after multiple imputation; \*Thresholds defined from the published literature, see methods. \*\*Included in French questionnaire; answers derived from free-text answers in other countries

**Table 4.** Risk ratios of elevated outpatient/inpatient and specialist service use at five years of age in children born very preterm by perinatal and social factors and country follow-up rates

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **N** | **Elevated outpatient/inpatient service use** | | | | | **Elevated specialist service use** | | | | |
|  | **Unadjusted\*** | | **Adjusted\*ⱡ** | |  | **Unadjusted\*** | | **Adjusted\*ⱡ** | |
| **%\*** | **RR** | **[95% CI]** | **RR** | **[95% CI]** | **%\*** | **RR** | **[95% CI]** | **RR** | **[95% CI]** |
| **Gestational age,** **completed weeks** |  |  |  |  |  |  |  |  |  |  |  |
| <26 | 298 | 52.9 | 1.38 | [1.19-1.60] | 1.21 | [1.01-1.44] | 72.6 | 1.85 | [1.43-2.40] | 1.48 | [1.16-1.90] |
| 26-27 | 653 | 43.5 | 1.12 | [1.04-1.20] | 1.02 | [0.93-1.13] | 56.0 | 1.39 | [1.25-1.54] | 1.21 | [1.09-1.35] |
| 28-29 | 923 | 45.8 | 1.15 | [1.02-1.29] | 1.14 | [1.01-1.30] | 49.9 | 1.23 | [1.06-1.44] | 1.16 | [1.01-1.33] |
| 30-31 | 1667 | 40.2 | ref |  | ref |  | 40.3 | ref |  | ref |  |
| **SGA (percentiles)** |  |  |  |  |  |  |  |  |  |  |  |
| <3rd | 763 | 47.2 | 1.10 | [0.99-1.23] | 1.07 | [0.92-1.26] | 50.7 | 1.06 | [0.98-1.15] | 1.08 | [0.95-1.22] |
| 3 – 9th | 411 | 37.8 | 0.87 | [0.78-0.97] | 0.89 | [0.82-0.98] | 50.0 | 1.04 | [0.96-1.12] | 1.12 | [1.02-1.22] |
| >10th | 2367 | 42.9 | ref |  | ref |  | 46.6 | ref |  | ref |  |
| **BPD** |  |  |  |  |  |  |  |  |  |  |  |
| No | 2992 | 41.9 | ref |  | ref |  | 45.4 | ref |  | ref |  |
| Yes | 462 | 51.1 | 1.28 | [1.16-1.43] | 1.14 | [1.05-1.23] | 65.2 | 1.55 | [1.39-1.73] | 1.18 | [1.10-1.26] |
| **Congenital anomalies** |  |  |  |  |  |  |  |  |  |  |  |
| No | 3247 | 42.0 | ref |  | ref |  | 46.7 | ref |  | ref |  |
| Yes | 294 | 56.4 | 1.23 | [1.04-1.44] | 1.17 | [1.00-1.37] | 60.8 | 1.23 | [1.11-1.36] | 1.16 | [1.04-1.30] |
| **Severe neonatal morbiditya** |  |  |  |  |  |  |  |  |  |  |  |
| No | 3103 | 41.7 | ref |  | ref |  | 44.8 | ref |  | ref |  |
| Yes | 357 | 55.6 | 1.27 | [1.17-1.38] | 1.14 | [1.03-1.26] | 76.3 | 1.69 | [1.51-1.89] | 1.44 | [1.35-1.53] |
| **Child sex** |  |  |  |  |  |  |  |  |  |  |  |
| Male | 1893 | 44.6 | 1.10 | [0.99-1.21] | 1.08 | [0.97-1.21] | 51.6 | 1.20 | [1.08-1.33] | 1.22 | [1.09-1.36] |
| Female | 1648 | 41.7 | ref |  | ref |  | 43.6 | ref |  | ref |  |
| **Multiple birth** |  |  |  |  |  |  |  |  |  |  |  |
| Singleton or one surviving multiple | 2505 | 44.9 | ref |  | ref |  | 48.5 | ref |  | ref |  |
| Multiples (twins, triplets or quadruplets) | 1036 | 39.1 | 0.87 | [0.78-0.98] | 0.89 | [0.78-1.02] | 46.4 | 0.94 | [0.84-1.07] | 1.01 | [0.86-1.17] |
| **Maternal education**b |  |  |  |  |  |  |  |  |  |  |  |
| Lower | 587 | 49.3 | 1.18 | [0.96-1.47] | 1.14 | [0.98-1.33] | 53.6 | 1.04 | [0.94-1.16] | 1.10 | [1.01-1.19] |
| Intermediate | 1447 | 44.6 | 1.15 | [1.04-1.28] | 1.13 | [1.02-1.26] | 46.3 | 1.01 | [0.89-1.14] | 1.03 | [0.97-1.09] |
| Higher | 1458 | 38.5 | ref |  | ref |  | 46.2 | ref |  | ref |  |
| **Employment status** |  |  |  |  |  |  |  |  |  |  |  |
| No parent unemployed | 3114 | 41.9 | ref |  | ref |  | 46.9 | ref |  | ref |  |
| At least one parent unemployed | 392 | 52.8 | 1.24 | [1.02-1.51] | 1.21 | [1.03-1.42] | 55.2 | 1.15 | [0.92-1.45] | 1.07 | [0.91-1.26] |
| **Maternal age at delivery** |  |  |  |  |  |  |  |  |  |  |  |
| ≤24 years | 418 | 45.2 | 0.99 | [0.84-1.17] | 0.90 | [0.73-1.10] | 45.6 | 0.94 | [0.81-1.10] | 0.88 | [0.76-1.03] |
| 25-34 years | 2021 | 44.7 | ref |  | ref |  | 48.6 | ref |  | ref |  |
| ≥35 years | 1092 | 38.8 | 0.88 | [0.81-0.96] | 0.88 | [0.80-0.96] | 47.9 | 1.00 | [0.92-1.08] | 1.02 | [0.94-1.10] |
| **Maternal country of birth** |  |  |  |  |  |  |  |  |  |  |  |
| Native | 2825 | 43.7 | ref |  | ref |  | 49.5 | ref |  | ref |  |
| European-born | 238 | 41.9 | 0.93 | [0.82-1.05] | 0.92 | [0.82-1.02] | 49.0 | 0.99 | [0.88-1.11] | 0.99 | [0.88-1.12] |
| Born outside Europe | 463 | 41.6 | 0.94 | [0.81-1.10] | 0.91 | [0.82-1.02] | 40.1 | 0.76 | [0.67-0.88] | 0.75 | [0.65-0.86] |
| **Parity** |  |  |  |  |  |  |  |  |  |  |  |
| Multiparous | 1372 | 43.3 | ref |  | ref |  | 47.9 | ref |  | ref |  |
| Nulliparous | 2129 | 43.1 | 1.04 | [0.90-1.20] | 1.04 | [0.87-1.24] | 48.1 | 1.01 | [0.92-1.11] | 1.01 | [0.89-1.15] |
| **Country routine follow-up rate**c |  |  |  |  |  |  |  |  |  |  |  |
| Lower | 1689 | 46.8 | ref |  | ref |  | 47.3 | ref |  | ref |  |
| Higher | 1852 | 39.2 | 0.67 | [0.48-0.94] | 0.69 | [0.50-0.95] | 48.6 | 0.91 | [0.72-1.15] | 0.96 | [0.76-1.20] |

\*Inverse probability weights after multiple imputation were used for all analyses.

**ⱡ** RRs for all adjustment variables are reported below

GA: Gestational age; SGA: small for gestational age; BPD: bronchopulmonary dysplasia

a Intraventricular hemorrhage grades III-IV, cystic periventricular leukomalacia, retinopathy of prematurity stages III-V or necrotizing enterocolitis requiring surgery

b Lower: ISCED levels 0–2 (lower secondary); intermediate: ISCED levels 3–5 (upper or post-secondary, non-tertiary or short cycle tertiary); higher: ISCED levels 6–8 (Bachelor degree or higher)

c Country routine follow-up rate is higher (at or above the mean of 27%): Portugal, Belgium, the Netherlands, France, Denmark and Sweden versus lower (below the mean): the UK, Germany, Estonia, Italy and Poland