

Online Table S2.3: Longitudinal (local/regional/national) surveys

Author	Country	Journal	Study type & dates	Number of patients	Ages	Disorders	Comments
Fauroux et al. [1]	France	Eur Respir J	1992-1933	287 children treated at home with O2, IV or NIV	< 18 yrs	153 children treated with NIV (24 cystic fibrosis, 87 NMD, 21 thoracic deformity) 5 children treated with CPAP	
Jardine et al. [2]	UK	BMJ	Cross-sectional survey, 1997, questionnaires	141 children	< 16 yrs	NIV or IV home: 52 NMD, 13 CCHS, 10 spinal injury, 9 craniofacial syndrome, 1 BPD, 8 other	52/141 treated at home with NIV
Kamm et al. [3]	Switzerland	Swiss Medical Weekly	Postal questionnaires	32 children (7 centres)	< 16 yrs	41% CCHS, 41% NMD, 6% craniofacial	19 NIV, 2 phrenic nerve pacing
Resener et al. [4]	Brazil	J Pediatr (Rio J)	April 1997-June 1998	26 children	1-21 yrs	No detail on NIV: 15 NMD, 8 central sleep apnea, 3 obstructive lung disease	
Fauroux et al. [5]	France	Pediatr Pulmonol	Cross-sectional national study, July 2000	102 children	0-18 yrs	35 NMD, 31 OSA, 17 cystic fibrosis, 9 CCHS, 8 scoliosis, 2 spina bifida, 1 encephalopathy	Only NIV
Edwards et al. [6]	Australia	J Pediatr Child Health	Retrospective survey at 1 center 1991-2004	108 treated with CPAP and 47 with NIV	0-17 yrs	17 NMD, 6 CNS, 2 CCHS, 2 mucopolysaccharidosis, 39 OSA, 11 cyphoscoliosis, 10 obesity, 5 airway	108 treated with CPAP and 47 with NIV

						malacia, 2 cystic fibrosis, 2 BPD, 5 bronchiectasis, 2 achondroplasia, 2 Down syndrome, 1 craniofacial syndrome, 24 other	
Graham et al. [7]	USA	Pediatrics	Retrospective survey in 1995 in the Massachusetts	197 children having chronic ventilatory support	For NIV 10.3 ± 6.6 yrs	98 treated with CPAP or BPAP: 55 NMD or CNS, 2 spinal cord injury, 6 BPD, 21 upper airway, 9 other 2 treated with negative pressure	
Oktem et al. [8]	Turkey (Istanbul)	Respiration	Longitudinal (2001-2006), 1 center in Istanbul	34 children	4 mo-17 yrs	For NIV: 18 BPD or airway problems, 3 NMD, (7 died)	23 NIV (11 IV)
Pekcan et al. [9]	Turkey	Turkish J Pediatr	Retrospective study in one center (4 yrs ?)	27 children on home MV: IV and NIV (no numbers)	0 - 15 yrs	16 NMD, 6 lung disease, 3 congenital heart disease, 2 storage disease No information on those on IV and NIV	
Tibbals et al. [10]	Australia	J Pediatr Child Health	Longitudinal (1979-2008), 1 center in Melbourne	168 children	3 w-19 yrs	No distinction IV vs NIV: 55 (32%) OSA, 42 NMD (25%), 23 (14%) tracheobronchomalacia, 20 (12%) cerebral palsy or scoliosis, 7 (4%) CCHS, 7 (4%) other central sleep apnea, +	58 CPAP, 50 BPAP, 48 tracheotomy, 5 phrenic nerve stimulation, 4 negative pressure, 3 nasopharyngeal tube

						other	
Goodwin et al. [11]	UK (SW)	Eur J Pediatr	Retrospective survey 1994-2009 South West of UK	106 children treated with home ventilation (IV and NIV)	< 18 yrs	63/106 treated with NIV:31 NMD, 21 upper airway, 9 CNS, 2 lung disease (no mention CPAP vs NIV)	
Racca et al. [12]	Italy	Pediatr Pulmonol	Postal questionnaires, NIV on January 2007	362 children	8-13 yrs	112 NMD, 52 BPD + upper airway, 17 encephalopathy, 19 central sleep apnea, 12 chest wall anomaly, 1 spinal cord injury	213 NIV
Wallis et al. [13]	UK	Arch Dis Child	Electronic based national questionnaire	933 children	< 17 yrs	25 CCHS, 47 other central sleep apnea, 6 cerebral palsy, 88 Duchenne, 69 SMA, 90 other NMD, 9 scoliosis, 14 BPD, 13 airway malacia, 58 Prader Will/obesity, 153 upper airway obstruction, 5 cystic fibrosis + other	704 (75%) NIV
Sovtic et al. [14]	Serbia	Pediatr Int	Longitudinal (2001-2011) in 1 center (Belgrade)	29 children	0.4-17.3 yrs	7 NMD, 4 cystic fibrosis, 5 OSA, 2 scoliosis or CCHS	18 NIV
Hsia et al. [15]	Taiwan	Pediatr Neonatol	Retrospective study in Taiwan	139 children	3m - 18 yrs	72% NMD, 14% airway/lung dysfunction, 12% metabolic/genetic	Only 3/139 children on NIV

						anomaly	
McDougall et al. [16]	Canada (Vancouver)	Arch Dis Child	Longitudinal (1995-2009), 1 center in Vancouver	144 children started on NIV	0-18 yrs	Decrease in NMD, increase in craniofacial/OSA	116 (81%) NIV, 22 CPAP, 94 BPAP, increase in NIV
Pavone et al. [17]	Italy (Rome)	Early Hum Development	1993-2012	Increase from 1 pt in 1993 to 100 in 2012	?	52 SMA, 26 other NMD, 15 cystic fibrosis, 30 obesity, 7 cerebral palsy, 21 Prader Willi syndrome, 17 encephalopathy, 6 CCHS + ROHHAD, 46 others	Only NIV
Amin et al. [18]	Canada (Toronto)	Pediatr Pulmonol	Longitudinal (1991-2011) in 1 center (Sick Kids Hospital)	379 children identified		35% musculoskeletal 36% respiratory disorders	313 NIV: increase 2x in IV, x10 in NIV
Preutthipan et al. [19]	Thailand	Curr Pediatr Rep	Retrospective data from 1 center	148 children	0-19 yrs	48% OSA, 15% NMD	64% NIV
Gupta et al. [20]	Nepal	J Nepal Pediatr Society	Longitudinal (2001-2012) in 1 center	24 children	?	?	4 NIV
Cancelinha et al. [21]	Portugal	Rev Port Pneumol	Retrospective data from 1 center	31 children	0 - 13 yrs	39% NMD, 23% metabolic disease, 19% central hypoventilation	NIV in 27 children
Han et al. [22]	Korea	PlosOne	Longitudinal (2001-2012) in 1 center (Seoul)	57 children with NMD		No diagnosis for the NIV patients	Only 9 NIV with 8 at home
Park et al. [23]	Korea	J Korean Med Sci	Data from the National	416 children	< 19 yrs, mean	IV: 202 (49%) NIV (51%): 146 NMD,	

			Health Insurance service in 2016	Prevalence 4.4/100000 children	age 6 yrs	46 CNS, 25 cardiopulmonary	
Chatwin et al. [24]	UK (London)	PlosOne	Longitudinal (1993-2011) in 1 center (Royal Brompton)	496 children started on home NIV	< 17 yrs 59 < 1 yr	56% NMD, 14% congenital syndrome, 9% upper airway anomaly, 5% BPD, 4% chest wall disease, 3% obesity, 3% central sleep apnea, 2% cardiac surgery, 4% other	Only NIV
Walsh et al. [25]	Ireland	Irish Med J	Questionnaires to pediatricians	Not available	??	Not available	Increase in NIV but no details
Rose et al. [26]	Canada	Respir Care	National web survey for home providers (2012-2013)	4334 ventilator-assisted patients	Adults and children, 425 (21%) < 18 yrs	Children: 30% muscular dystrophy, 30% central hypoventilation, 12% obesity, 10% chest wall, 6% neurological disease, 6% other	73% NIV
Weiss et al. [27]	Austria	Klin Pediatr	National cross-sectional study (questionnaire) on June 2013	143	143, 111 (78%) < 18 yrs	44% NMD, 19% other NMD, 9% central sleep apnea, 8% OSA, 8% thorax and spinal disease, 5% lung disease, 6% other	95/143 on NIV, 6% CPAP
Nathan et al. [28]	Malaysia	Pediatr Pulmonol	Longitudinal study in 1 center (2001-2014)	70 (2 pts in 2001 to 47 in 2014)	1.1 - 11 yrs for NIV	32 lung disease, 5 upper airway, 7 NMD, 4 chest/spine disease, 1 cardiac, 1 central sleep	60 patients on NIV: 30 CPAP + 30 BPAP

						apnea, 5 spinal cord injury	
Chau et al. [29]	Hong Kong	Respir Care	Longitudinal study in 1 center (1997-2015)	96 patients	< 21 yrs	NIV: 40 NMD, 13 upper airway anomaly, 6 BPD, 1 chest wall deformity, 11 central sleep apnea + metabolic + neurological + genetic disorder	71 NIV (34%): 16 CPAP, 55 BPAP
Van der Poel et al. [30]	South Africa	Pediatr Allergy Immunol Pulmonol	Retrospective study in 1 center	55 children	3 m - 18 yrs	60% NMD	16 (29%) NIV
Ikedo et al. [31]	Japan	Brain Development	Longitudinal study in 1 center (2001-2015)	53 patients	< 20 yrs	36 NMD, 23 congenital anomaly, 17 metabolic disease, 11 perinatal disorder, and other	All NIV
Castro-Codesal et al. [32]	Canada	PlosOne	Retrospective multicenter cohort (2005-2014) in Alberta: x6 increase	622 children	< 18 yrs	371 (60%) upper airway, 107 (17%) CNS, 93 (15%) musculoskeletal and NMD, 39 (6%) cardiorespiratory disease, 12 (2%) other	All NIV: 75% CPAP, 22% BPAP
Leske et al. [33]	Argentina	Pediatr Pulmonol	Longitudinal study in 1 center (2007-2018) Buenos Aires	244 children	3 - 14 yrs	No distinction IV vs NIV: 105 (43%) NMD, 56 (23%) genetic sd (achondroplasia, Prader Willi syndrome, craniostenosis, mucopolysaccharidosis, Down syndrome,	210 (86%) NIV: 21% CPAP

						Treacher Collins, 18 obesity, 11 CCHS 4 BPD, 4 ROHHAD, 17 other	
Hassani et al. [34]	Iran	Anestezjologia Intensywna Terapia	Retrospective study in 1 center	67 children	2 m – 15 yrs	45% lung disease, 31% NMD, 13% metabolic disease	62 (93%) NIV

Abbreviations: IV: invasive ventilation, NIV: noninvasive ventilation, CPAP: continuous positive airway pressure, BPAP: bilevel positive airway pressure, NMD: neuromuscular disease, SMA: spinal muscular atrophy, OSA: obstructive sleep apnea, CCHS: central congenital hypoventilation syndrome, BPD: bronchopulmonary dysplasia, CNS: central nervous system, ROHHAD syndrome: rapid-onset obesity with hypoventilation, hypothalamic dysfunction, and autonomic dysregulation syndrome.

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