

Table 1.a: *Clinical expertise of healthcare providers participating in Content Validation (Phase 2)*

Healthcare professions	Healthcare professions N (%)	Units	Clinical Conditions <i>Examples of the conditions in which the interviewed healthcare providers have expertise</i>
Nursing professions *	3	Broncopedumatology and Cystic Fibrosis	Cystic Fibrosis Spinal muscular atrophy Chronic respiratory failure with invasive OR non invasive ventilation, OR with tracheostomy, Central alveolar hypoventilation (Ondine syndrome) Disorders of thoracic cage (e.g. kyphoscoliosis) ± Obesity) Muscular dystrophies and myopathies, Bronchopulmonary dysplasia Pulmonary fibrosis Central hypoventilation (congenital or acquired))
Nursing professions	3	Cardiology	Heart Failure, Congenital anomalies of the heart and great vessels Cardiomyopathy (eg. Hypertrophic obstructive cardiomyopathy) End-stage heart disease (cardiomyopathy/heart failure) awaiting heart transplantation Heart transplant status Complete atrioventricular block Single ventricle Bulbus cordis anomalies and cardiac septal closure defects Congenital tricuspid atresia and stenosis Ebstein anomaly

			Hypoplastic left heart syndrome Unspecified cardiac anomaly Pulmonary artery anomalies Other second-degree atrioventricular block Atrial fibrillation Ventricular fibrillation Complete transposition of the great vessels (arteries) Other transposition of the great vessels Unspecified pulmonary valve anomaly Other pulmonary valve anomalies Congenital heart block Aortic atresia and stenosis Total anomalous pulmonary venous connection (TAPVC) Partial anomalous pulmonary venous connection (PAPVC)
Nursing professions	3	Neonatal and Paediatric Surgery	Congenital or acquired diseases of the gastrointestinal tract ± Presence of artificial opening (eg.gastrostomy, colostomy) Fecal incontinence due to congenital anorectal malformation Short bowel syndrome (postsurgical malabsorption) Mandibulofacial dysostosis (Treacher Collins syndrome) Late effects of injury (post-traumatic sequelae) Unspecified anomalies of the great veins Hirschsprung disease and other congenital functional disorders of the colon Anomalies of the skull and facial bones

			Chronic ulcerative ileocolitis Unspecified abdominal wall anomaly
Nursing professions	3	Hepatogastroenterology and Nutrition	Unspecified chronic liver disease (without mention of alcohol) Liver transplant status Biliary atresia Glycogen storage disease (Glycogenosis) Cholangitis (including sclerosing cholangitis)
Nursing professions	3	General and specialized paediatrics (e.g. Rheumatology, Metabolic diseases)	Vascular disorders of skin Circumscribed scleroderma Juvenile rheumatoid arthritis Combined immunity deficiency Other humoral immunodeficiency Other cellular immunodeficiency Phenylketonuria Glycogen storage disease Galactosemia Regional enteritis, site unspecified Ulcerative colitis limited to the colon
Nursing professions	3	Emergency Pediatrics	All the chronic and complex conditions with acute symptoms or complications
Nursing professions	3	Nephrology and Dialysis	Chronic renal failure End stage renal disease (ESRD) (on hemodialysis or peritoneal dialysis) Kidney transplant status (pre- or post-renal transplant)

Nursing professions	2	Neurology and Pediatric Rehabilitation	Epilepsy, unspecified, with intractable epilepsy Late effects of intracranial injury Late effects of spinal cord injury Late of effects of submersion Late effects of intrauterine hypoxia and birth asphyxia Late effects of neoplasm of brain Late effects of inflammatory diseases of central nervous system / peripheral nervous system Hereditary spastic paraplegia Werdnig–Hoffmann disease Hereditary progressive muscular dystrophy Spinal muscular atrophy, unspecified Kugelberg–Welander disease Other spinal muscular atrophies Friedreich ataxia Congenital diplegia Congenital hemiplegia Congenital quadriplegia Infantile hemiplegia Amyotrophic lateral sclerosis
Nursing professions	2	Neonatal Intensive Care and Sub-Intensive Care with Follow up	Epidermolysis bullosa Disorders relating to short gestation and low birthweight ± Respiratory distress syndrome in newborn Late effects of necrotizing enterocolitis of newborn

			high dependence patients (e.g ventilatory or artificial nutrition) Atresia and stenosis of the small intestine Diaphragmatic anomalies Obstructive cardiac anomalies, not elsewhere classified Other congenital anomalies of the abdominal wall
Nursing professions	2	Trial Center, Imaging Area	All the diagnoses described in these clinical settings
Nursing professions	1	Hepato-Biliary-Pancreatic Surgery and Liver and Kidney Transplantation	Liver cirrhosis without mention of alcohol Biliary cirrhosis Other nonalcoholic chronic liver disease Chronic persistent hepatitis Other chronic hepatitis Biliary atresia Other anomalies of the gallbladder, bile ducts, and liver
Nurse Counsellor	2	Department of Cardiac Surgery, Cardiology and Heart-Lung Transplant	All the diagnoses described in Cardiology Units
Physician	1	Pediatric Palliative Care Center	They deliver care to patients across all clinical settings requiring pediatric palliative care
Physician	2	Digestive Endoscopy	Short bowel syndrome ± parenteral nutrition Microvillus inclusion disease (congenital enteropathy) Chronic intestinal pseudo-obstruction Hirschsprung's disease (congenital

			megacolon) Late effects of diseases of the esophagus (congenital or acquired) Regional enteritis of the small intestine Regional enteritis of the large intestine Regional enteritis of both small and large intestine Chronic ulcerative enterocolitis Ulcerative pancolitis Other ulcerative colitis Ulcerative colitis, unspecified
Physician	1	Hepatogastroenterology and nutrition	Liver cirrhosis without mention of alcohol Biliary cirrhosis Other nonalcoholic chronic liver disease Chronic persistent hepatitis Other chronic hepatitis Biliary atresia Other anomalies of the gallbladder, bile ducts, and liver
Physician	1	Diabetology and Growth Pathology	Lipodystrophy Polyostotic fibrous dysplasia of bone
Physician	1	Neonatal Nutrition Education and Donor Human Milk Bank	All the described diagnosis for Neonatal Units
Physician	2	Rare diseases and Medical genetics	Unspecified congenital anomalies Diastematomyelia

			Other anomalies of the aorta Osteodystrophy, unspecified Chondroectodermal dysplasia Multiple epiphyseal dysplasia Other osteodystrophies Marfan syndrome Wiskott–Aldrich syndrome Nezelof syndrome Carnitine deficiency due to inborn errors of metabolism
Physician	1	Pediatrics with high care complexity	Congenital hereditary muscular dystrophy Tracheoesophageal fistula, esophageal atresia and stenosis Multiple congenital anomalies, so described Progressive muscular atrophy Progressive bulbar palsy Anomalies of the aortic arch Other anomalies of the great veins
Physician	1	Emergency Pediatrics	All the chronical and complex conditions with acute symptoms or complications
Physician	1	Heart Failure, Transplant, and Mechanical Cardio-Respiratory Assistance	End-stage heart disease (cardiomyopathy/heart failure) awaiting heart transplantation Idiopathic myocarditis (including giant cell myocarditis) ± Presence of ventricular assist device (LVAD) Dilated cardiomyopathy ± LVAD Heart transplant status Double outlet right ventricle

			Hypertrophic obstructive cardiomyopathy Becker muscular dystrophy Myocardial degeneration
Physician	1	Pediatric Urology	Exstrophy of urinary bladder Spina bifida (myelomeningocele) ± Neurogenic bladder Congenital urethral valves), Prune Belly syndrome
Psychologist	1	Pediatric Palliative Care Center	They take care of the patients and families of all the clinical settings with specialistic pediatric palliative care needs
Psychologist	9	Clinical psychology	They take care of the patients and families of previous described clinical settings regarding the emotional and behaviours issues
Rehabilitation Therapist	5	Pediatric Rehabilitation	They take care of the patients of previous described clinical settings regarding the rehabilitation treatment and education
Respiratory Rehabilitation Therapist	1	Respiratory physical therapy	They take care of the patients of previous described clinical settings regarding the respiratory rehabilitation treatment and education
Dietitian	5	Nutritional Rehabilitation	They take care of the patients of previous described clinical settings regarding the dietetical treatment and education