

SCHEDULE 4

Regulations 7, 10 and 11

Services for rare and very rare conditions

Interpretation

1. For the purposes of this Schedule—

- (a) an individual is a child if they have not yet attained the age of 18 years old;
- (b) an individual is a young person if they are aged 13 years old or over but have not yet attained the age of 21 years old; and
- (c) an individual is an adult if they are aged 18 years old or over,

unless, for the purposes of a service specified in this Schedule, the Board, or the person providing such a service pursuant to a commissioning contract with the Board, considers on clinical grounds that an individual should otherwise be treated as a child, a young person or an adult.

The services

- 2.** Adult ataxia telangiectasia services.
- 3.** Adult congenital heart disease services.
- 4.** Adult highly specialist pain management services.
- 5.** Adult highly specialist respiratory services.
- 6.** Adult highly specialist rheumatology services.
- 7.** Adult secure mental health services.
- 8.** Adult specialist cardiac services.
- 9.** Adult specialist eating disorder services.
- 10.** Adult specialist endocrinology services.
- 11.** Adult specialist intestinal failure services.
- 12.** Adult specialist neurosciences services.
- 13.** Adult specialist ophthalmology services.
- 14.** Adult specialist orthopaedic services.
- 15.** Adult specialist pulmonary hypertension services.
- 16.** Adult specialist renal services.
- 17.** Adult specialist services for patients infected with HIV.
- 18.** Adult specialist vascular services.
- 19.** Adult thoracic surgery services.
- 20.** Alkaptonuria service.
- 21.** Alström syndrome service.
- 22.** Ataxia telangiectasia service for children.
- 23.** Autoimmune paediatric gut syndromes service.
- 24.** Autologous intestinal reconstruction service for adults.

25. Bardet-Biedl syndrome service.
26. Barth syndrome service.
27. Beckwith-Wiedemann syndrome with macroglossia service.
28. Behcet's syndrome service.
29. Bladder exstrophy service.
30. Blood and marrow transplantation services.
31. Bone anchored hearing aid services.
32. Breast radiotherapy injury rehabilitation service.
33. Child and adolescent mental health services – Tier 4.
34. Choriocarcinoma service.
35. Chronic pulmonary aspergillosis service.
36. Cleft lip and palate services.
37. Cochlear implantation services.
38. Complex childhood osteogenesis imperfecta service.
39. Complex Ehlers Danlos syndrome service.
40. Complex neurofibromatosis type 1 service.
41. Complex spinal surgery services.
42. Complex tracheal disease service.
43. Congenital hyperinsulinism service.
44. Craniofacial service.
45. Cryopyrin associated periodic syndrome service.
46. Cystic fibrosis services.
47. Diagnostic service for amyloidosis.
48. Diagnostic service for primary ciliary dyskinesia.
49. Diagnostic service for rare neuromuscular disorders.
50. Encapsulating peritoneal sclerosis treatment service.
51. Epidermolysis bullosa service.
52. Extra corporeal membrane oxygenation service for adults.
53. Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure.
54. Ex-vivo partial nephrectomy service.
55. Fetal medicine services.
56. Gender identity development service for children and adolescents.
57. Gender identity disorder services.
58. Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support).

59. Highly specialist adult urinary and gynaecological surgery services.
60. Highly specialist allergy services.
61. Highly specialist colorectal surgery services.
62. Highly specialist dermatology services.
63. Highly specialist metabolic disorder services.
64. Highly specialist pain management services for children and young people.
65. Highly specialist palliative care services for children and young people.
66. Highly specialist services for adults with infectious diseases.
67. Hyperbaric oxygen treatment services.
68. Insulin-resistant diabetes service.
69. Islet transplantation service.
70. Liver transplantation service.
71. Lymphangiomyomatosis service.
72. Lysosomal storage disorder service.
73. Major trauma services.
74. McArdle's disease service.
75. Mental health service for deaf children and adolescents.
76. Middle ear implantable hearing aid services.
77. Neurofibromatosis type 2 service.
78. Neuromyelitis optica service.
79. Neuropsychiatry services.
80. Ocular oncology service.
81. Ophthalmic pathology service.
82. Osteo-odonto-keratoprosthesis service for corneal blindness.
83. Paediatric and perinatal post mortem services.
84. Paediatric cardiac services.
85. Paediatric intestinal pseudo-obstructive disorders service.
86. Pancreas transplantation service.
87. Paroxysmal nocturnal haemoglobinuria service.
88. Positron Emission Tomography – Computed Tomography services.
89. Primary ciliary dyskinesia management service.
90. Primary malignant bone tumours service.
91. Proton beam therapy service.
92. Pseudomyxoma peritonei service.
93. Pulmonary hypertension service for children.

- 94. Pulmonary thromboendarterectomy service.
- 95. Radiotherapy services.
- 96. Rare mitochondrial disorders service.
- 97. Reconstructive surgery service for adolescents with congenital malformation of the female genital tract.
- 98. Retinoblastoma service.
- 99. Secure forensic mental health service for young people.
- 100. Severe acute porphyria service.
- 101. Severe combined immunodeficiency and related disorders service.
- 102. Severe intestinal failure service.
- 103. Severe obsessive compulsive disorder and body dysmorphic disorder service.
- 104. Small bowel transplantation service.
- 105. Specialist burn care services.
- 106. Specialist cancer services.
- 107. Specialist cancer services for children and young people.
- 108. Specialist dentistry services for children and young people.
- 109. Specialist ear, nose and throat services for children and young people.
- 110. Specialist endocrinology and diabetes services for children and young people.
- 111. Specialist gastroenterology, hepatology and nutritional support services for children and young people.
- 112. Specialist genetic services.
- 113. Specialist gynaecology services for children and young people.
- 114. Specialist haematology services for children and young people.
- 115. Specialist haemoglobinopathy services.
- 116. Specialist immunology services for patients with deficient immune systems.
- 117. Specialist mental health services for deaf adults.
- 118. Specialist morbid obesity services.
- 119. Specialist neonatal care services.
- 120. Specialist neuroscience services for children and young people.
- 121. Specialist ophthalmology services for children and young people.
- 122. Specialist orthopaedic surgery services for children and young people.
- 123. Specialist paediatric intensive care services.
- 124. Specialist paediatric liver disease service.
- 125. Specialist perinatal mental health services.
- 126. Specialist plastic surgery services for children and young people.
- 127. Specialist rehabilitation services for patients with highly complex needs.

- 128. Specialist renal services for children and young people.
- 129. Specialist respiratory services for children and young people.
- 130. Specialist rheumatology services for children and young people.
- 131. Specialist services for children and young people with infectious diseases.
- 132. Specialist services for complex liver, biliary and pancreatic diseases in adults.
- 133. Specialist services for haemophilia and other related bleeding disorders.
- 134. Specialist services for severe personality disorder in adults.
- 135. Specialist services to support patients with complex physical disabilities.
- 136. Specialist surgery for children and young people.
- 137. Specialist urology services for children and young people.
- 138. Spinal cord injury services.
- 139. Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders.
- 140. Stickler syndrome diagnostic service.
- 141. Vein of Galen malformation service.
- 142. Veterans' post traumatic stress disorder programme.
- 143. Wolfram syndrome service.
- 144. Xeroderma pigmentosum service.