Additional file 1

Table S1. Population inputs in the model

|  |  |  |
| --- | --- | --- |
| Population inputs | Value |  Reference |
| General population, UK | 65,110,034 | Office for National Statistics, 2015[[1](#_ENREF_1)] |
| Prevalence of CHI | 0.003% | Estimated scope of the national CHI service (NHS England CHI Service Standard Contract, 2013)[[2](#_ENREF_2)] |
| Number of newly diagnosed patients with CHI per year | 95 | Expert opinion, (GOSH, 2015; NORCHI, 2016)[[3](#_ENREF_3),[4](#_ENREF_4)] |
| Maximum age of patients that have received a near-total pancreatectomy | 54 | Harold N. Lovvorn III, 1999 [[5](#_ENREF_5)] |

Table S2. Cost inputs in the model

|  |  |  |
| --- | --- | --- |
| Cost inputs | Value | Reference |
| Neonatal care |
| Cost of neonatal care, per non-elective long stay | £1,292.69 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of neonatal care (excess) | £274.11 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| CHI patients treated and discharged at local hospital  |
| Cost of inpatient care, per non-elective long stay at local hospital | £2,186.61 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of inpatient care at local hospital (excess) | £486.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] a |
| CHI patients who are transferred to specialist centre for treatment |
| Cost of transfer from local hospital to specialist centre, per journey | £990.19 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of insertion of central venous catheter (Hickman line) | £5,925.98 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of genetic testing (KATP analysis) | £1,000.00 | UK Genetic Testing Network 2017[[7](#_ENREF_7)] |
| Cost of inpatient care, per non-elective long stay at specialist centre | £2,186.61 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of inpatient care at specialist centre (excess) | £486.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] a |
| Cost of a multidisciplinary team meeting to discuss genetic testing (KATP) results | £107.35 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] b |
| Cost of 18F-DOPA-PET-CT scan, direct access | £2,149.97 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of 18F-DOPA-PET-CT scan, outpatient procedure | £544.63 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of transfer from specialist centre to 18F-DOPA-PET-CT scan, per journey | £236.44 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| CHI patients with focal disease  |
| Daily cost of inpatient care at specialist centre | £486.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] a |
| Cost of a multidisciplinary team meeting to discuss scan results and surgical approach | £107.35 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] b |
| Cost of a laparoscopic lesionectomy | £3,234.15 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of an open lesionectomy | £8,117.84 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of bed days for laparoscopic lesionectomy (excess) | £380.64 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of bed days for open lesionectomy (excess) | £352.48 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of removal of central venous catheter (Hickman line), day case | £1,162.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of a multidisciplinary team meeting to discuss discharge from inpatient care | £107.35 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] b |
| CHI patients with diffuse disease, medically managed |
| Daily cost of inpatient care at specialist centre | £486.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] a |
| Daily cost of subcutaneous octreotide | £27.50 | Expert opinion (GOSH), 2015\* [[3](#_ENREF_3)] |
| Cost of gastrostomy insertion | £1,074.43 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of removal of central venous catheter (Hickman line), day case | £1,162.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of a multidisciplinary meeting to discuss discharge from inpatient care | £107.35 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] b |
| CHI patients with diffuse disease, surgically managed |
| Daily cost of inpatient care at specialist centre (excess) | £486.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] a |
| Daily cost of subcutaneous octreotide | £27.50 | Expert opinion (GOSH), 2015\* [[3](#_ENREF_3)] |
| Cost of a multidisciplinary team meeting to discuss scan results and surgical approach | £107.35 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] b |
| Cost of first near-total pancreatectomy (without complications) | £6,737.17 | NHS Reference Costs 2015-16[[6](#_ENREF_6)]  |
| Cost of first near-total pancreatectomy (with intraoperative and nonbiliary postoperative complications) | £9,225.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] c |
| Cost of second near-total pancreatectomy (with complications) | £9,225.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] c |
| Cost of choledochoduodenostomy | £3,881.93 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of bed days for near-total pancreatectomy, no complications (excess) | £396.31 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of bed days for near-total pancreatectomy, complications (intraoperative and nonbiliary postoperative) (excess) | £298.93 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Daily cost of bed days for re-treatment with second near-total pancreatectomy (excess) | £298.93 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of closure of gastrostomy | £860.11 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of removal of central venous catheter (Hickman line), day case | £1,162.62 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of a multidisciplinary team meeting to discuss discharge from inpatient care | £107.35 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] b |
| Post-discharge, CHI patients treated and discharged at local hospital |
| Cost of diazoxide (Eudemine®) per 50 mg tablet | £0.46 | BNF (February 2017)[[8](#_ENREF_8)] |
| Post-discharge, CHI patients with diffuse disease, medically managed |
| Daily cost of subcutaneous octreotide | £770.11 | Expert opinion (GOSH), 2015\* [[3](#_ENREF_3)] |
| Cost of lanreotide (Somatuline Autogel®) per 120 mg/mL pre-filled syringe | £551.00 | BNF (February 2017); Expert opinion (GOSH), 2015[[3](#_ENREF_3),[8](#_ENREF_8)] |
| Yearly cost of needles for multiple daily injections | £35.38 | Cummins, 2010 [Cost year NS]\* [[9](#_ENREF_9)] |
| Cost of insulin pump, per device | £2,626.12 | Cummins, 2010 [Cost year NS]\* [[9](#_ENREF_9)] |
| Yearly cost of infusion sets, reservoirs | £1,342.36 | Cummins, 2010 [Cost year NS]\* [[9](#_ENREF_9)] |
| Cost of a self-measured blood glucose test | £0.34 | Evans, 2015 [Cost year 2013]\* [[10](#_ENREF_10)] |
| Cost of a gastrostomy pump, for continuous feeds | £774.74 | Fresenius Kabi Price List, March 2017[[11](#_ENREF_11)] |
| Cost of closure of gastrostomy | £860.11 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of a gallbladder ultrasound scan | £55.14 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of gallbladder pathology treatment, ursodeoxycholic acid, per 60 x 150 mg tablets  | £14.49 | BNF (February 2017)[[8](#_ENREF_8)] |
| Daily cost of inpatient care | £808.99 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Post-discharge, CHI patients with diffuse disease, surgically managed |
| Cost of gastrostomy pump, for continuous feeds | £774.74 | Fresenius Kabi Price List, March 2017[[11](#_ENREF_11)] |
| Cost of closure of gastrostomy | £860.11 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of pancreatic exocrine assessment, sample taken at outpatient follow-up | £7.63 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of pancreatic enzyme replacement therapy, Pancrex® V, per 300 capsules | £53.20 | BNF (February 2017)[[8](#_ENREF_8)] |
| Cost of pancreatic enzyme replacement therapy, CREON® 25000, per 100 capsules | £28.25 | BNF (February 2017)[[8](#_ENREF_8)] |
| Post-discharge diabetes mellitus care for CHI patients with diffuse disease, surgically managed  |
| Cost of paediatric outpatient diabetes care, per patient, per year | £2,925.00 | NHS National Tariff 2016-17[[12](#_ENREF_12)] |
| Total cost of insulin treatment for patients with IDDM managed by multiple daily insulin injections (including severe and non-severe events) per year | £2,183.00 | Evans, 2015 (2013)\* [[10](#_ENREF_10)] |
| Average annual cost of insulin treatment with continuous subcutaneous insulin infusions | £2,858.87 | Cummins, 2010 [Cost year NS]\* [[9](#_ENREF_9)] |
| Cost of a hospital admission due to diabetes (excluding hypoglycaemic episode admission) | £2,136.83 | Cummins, 2010 [Cost year NS]\* [[9](#_ENREF_9)] |
| Cost of a hospital admission due to a hypoglycaemic episode | £837.04 | Cummins, 2010 [Cost year NS]\* [[9](#_ENREF_9)] |
| Follow-up visits for all patients |
| Cost of a follow-up outpatient visit | £228.68 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Cost of annual cognitive assessment  | £597.52 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |

\*Cost inflated to 2015/2016 cost year using the Personal Social Services Research Unit’s (PSSRU) hospital and community health services (HCHS) index[[13](#_ENREF_13)]

aCost input shares a cost reference described as “Paediatric Endocrine Disorders, excluding Diabetes Mellitus, with CC score 0”

bCost input shares a cost reference described as “Other Cancer Multidisciplinary Team Meetings”

cCost input shares a cost reference described as “Very Major Open, Hepatobiliary or Pancreatic Procedures, with CC Score 3”

Table S3. Clinical inputs in the model

|  |  |  |
| --- | --- | --- |
| Clinical inputs | Value | Reference |
| Neonatal care |
| Number of days to assess response to medical treatment in neonatal care | 10 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Proportion of CHI patients responsive to first-line therapy at local hospital | 75% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients requiring further investigation/treatment at specialist centre | 25% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Average number of days in neonatal care | 2.79 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| CHI patients treated and discharged at local hospital  |
| Number of days until discharge from hospital following successful first-line therapy | 14 | Expert opinion (GOSH, 2015; NORCHI, 2016)[[3](#_ENREF_3),[4](#_ENREF_4)]  |
| Average number of days in inpatient care at local hospital | 2.59 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| CHI patients, transferred to specialist centre for treatment |
| Number of days until receive genetic testing result (KATP analysis)  | 10 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Minimum number of days from receiving genetic testing result to 18F-DOPA-PET-CT scan | 22 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Proportion of CHI patients with genetically confirmed diffuse disease (GDH-HI, GK-H1) | 53% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients requiring further testing (18F-DOPA-PET-CT scan) | 47% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients with direct access to 18F-DOPA-PET-CT scan i.e. NORCHI | 47% | Expert opinion (GOSH, 2015; NORCHI, 2016)[[3](#_ENREF_3),[4](#_ENREF_4)] |
| Proportion of CHI patients without direct access to 18F-DOPA-PET-CT scan, i.e. GOSH | 54% | Expert opinion (GOSH, 2015; NORCHI, 2016)[[3](#_ENREF_3),[4](#_ENREF_4)]  |
| Proportion of CHI patients with diffuse disease on 18F-DOPA-PET-CT scan | 66% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients with identified focal disease on 18F-DOPA-PET-CT scan | 34% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Average number of days in inpatient care at specialist centre for insertion of central venous catheter (Hickman line) | 2.36 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Average number of days in inpatient care at specialist centre | 2.59 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| CHI patients with focal disease |
| Number of days from focal disease diagnosis, i.e. scan results, to surgery | 17.5 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Number of days to discharge from laparoscopic lesionectomy | 7 | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Number of days to discharge from open lesionectomy | 10 | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients undergoing laparoscopic lesionectomy | 40% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients undergoing open lesionectomy | 60% | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Average number of days in hospital for a laparoscopic lesionectomy | 1.86 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Average number of days in hospital stay for an open lesionectomy | 4.41 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| CHI patients with diffuse disease, medically managed |
| Number of days to assess response to octreotide | 8.5 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Number of days from assessment of response to octreotide to discharge | 1 | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients with diffuse disease responsive to octreotide | 30% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients with diffuse disease unresponsive to octreotide i.e. require near-total pancreatectomy | 70% | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Proportion of CHI patients responsive to octreotide requiring gastrostomy | 7.5% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients not responsive to octreotide requiring gastrostomy | 15% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| CHI patients with diffuse disease, surgically managed |
| Number of days from octreotide non-response until surgery | 21 | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Number of days on octreotide therapy until surgery | 19 | Arnoux, 2011[[15](#_ENREF_15)] |
| Number of days until discharge after a near-total pancreatectomy (without complications) | 10 | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Number of days until discharge after a near-total pancreatectomy (with intraoperative and nonbiliary postoperative complications) | 21 | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Number of days until discharge after a near-total pancreatectomy (with biliary postoperative complications) | 31.5 | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Number of days from first surgery to second surgery | 17.5 | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Number of days until discharge after re-treatment with a second near-total pancreatectomy | 31.5 | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients undergoing near-total pancreatectomy (without complications) | 54% | McAndrew, 2003[[16](#_ENREF_16)] |
| Proportion of CHI patients undergoing near-total pancreatectomy (with intraoperative and nonbiliary postoperative complications)  | 35% | McAndrew, 2003[[16](#_ENREF_16)] |
| Proportion of CHI patients undergoing near-total pancreatectomy (with biliary postoperative complications)  | 10% | McAndrew, 2003[[16](#_ENREF_16)] |
| Proportion of CHI patients still requiring gastrostomy post-near-total pancreatectomy | 33% | Cade, 1998[[17](#_ENREF_17)] |
| Proportion of CHI patients no longer requiring gastrostomy post-near-total pancreatectomy | 67% | Cade, 1998[[17](#_ENREF_17)] |
| Proportion of CHI patients requiring re-treatment with second near-total pancreatectomy | 45% | Expert opinion (GOSH and NORCHI), 2016[[4](#_ENREF_4),[14](#_ENREF_14)] |
| Average number of days in hospital for a near-total pancreatectomy (without complications) | 4.16 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Average number of days in hospital for a near-total pancreatectomy (with intraoperative and nonbiliary complications) | 7.48 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Average number of days in hospital for re-treatment with a second near-total pancreatectomy | 7.48 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Average number of days in hospital for a choledochoduodenostomy | 2.27 | NHS Reference Costs 2015-16[[6](#_ENREF_6)] |
| Post-discharge, CHI patients treated and discharged at local hospital |
| Average weight of patient in year 1, kg | 7.11 | WHO, 2017[[18](#_ENREF_18)] |
| Average weight of patient, years 2–5, kg | 14.08 | WHO, 2017[[18](#_ENREF_18)] |
| Post-discharge, CHI patients with diffuse disease, medically managed |
| Average dose of octreotide, μg/kg/day | 17.8 | Demirbilek, 2014[[19](#_ENREF_19)] |
| Daily number of self-measured blood glucose tests for octreotide therapy | 7.5 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of inpatient bed days for octreotide therapy | 6 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of inpatient bed days for lanreotide therapy in the first and second year | 6 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of inpatient bed days for lanreotide therapy after the second year | 3 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Proportion of CHI patients receiving octreotide by continuous infusion | 0% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients receiving octreotide by multiple daily injections | 100% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients receiving bolus gastrostomy feeds only | 30% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients receiving continuous gastrostomy feeds | 70% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients switching from octreotide to lanreotide after first year | 50% | Expert opinion, (NORCHI), 2017[[20](#_ENREF_20)] |
| Proportion of CHI patients continuing with octreotide after first year | 50% | Expert opinion (NORCHI), 2017[[20](#_ENREF_20)] |
| Number of gallbladder ultrasound scans in the first year | 3 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of gallbladder ultrasound scans after the first year | 3 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Proportion of patients on octreotide developing gallbladder pathology | 32% | Demirbilek, 2014[[19](#_ENREF_19)] |
| Median weight of CHI patient at 3 months, kg | 6.40 | WHO, 2017[[18](#_ENREF_18)] |
| Median weight of CHI patient at 12 months, kg | 9.60 | WHO, 2017[[18](#_ENREF_18)] |
| Median weight of CHI patient at 24 months, kg | 12.20 | WHO, 2017[[18](#_ENREF_18)] |
| Post-discharge, CHI patients with diffuse disease, surgically managed |
| Proportion of CHI patients still requiring gastrostomy post-surgery | 33% | Cade, 1998[[17](#_ENREF_17)] |
| Proportion of CHI patients cured post-pancreatectomy | 18% | Arya, 2014[[21](#_ENREF_21)] |
| Proportion of CHI patients successfully managed with octreotide post-near-total pancreatectomy | 33% | Arya, 2014[[21](#_ENREF_21)] |
| Proportion of CHI patients successfully managed with diazoxide post-near-total pancreatectomy | 7% | Arya, 2014[[21](#_ENREF_21)] |
| Proportion of CHI patients successfully managed with regular daytime and overnight feeds post-near-total pancreatectomy | 16% | Arya, 2014[[21](#_ENREF_21)] |
| Proportion of CHI patients receiving bolus gastrostomy feeds only | 30% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients receiving continuous gastrostomy feeds | 70% | Expert opinion (GOSH), 2016[[14](#_ENREF_14)] |
| Proportion of CHI patients requiring pancreatic enzyme supplementation post-surgery | 49% | Arya, 2014[[21](#_ENREF_21)] |
| Post-discharge diabetes mellitus care for CHI patients with diffuse disease, surgically managed  |
| Proportion of CHI patients requiring transient insulin therapy immediately post-near-total pancreatectomy | 9% | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM immediately post-near-total pancreatectomy | 0.13 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 1 year post-near-total pancreatectomy | 0.18 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 2 years post-near-total pancreatectomy | 0.04 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 3 years post-near-total pancreatectomy | 0.04 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 4 years post-near-total pancreatectomy | 0.09 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 5 years post-near-total pancreatectomy | 0.13 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 6 years post-near-total pancreatectomy | 0.09 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 7 years post-near-total pancreatectomy | 0.18 | Arya, 2014[[21](#_ENREF_21)] |
| Incidence of IDDM at 11 years post-near-total pancreatectomy | 0.96 | Arya, 2014[[21](#_ENREF_21)] |
| Proportion of CHI patients with IDDM managed by multiple daily injections  | 90% | Expert opinion (GOSH, 2015; NORCHI, 2016)[[3](#_ENREF_3),[4](#_ENREF_4)] |
| Proportion of CHI patients managed by continuous subcutaneous insulin infusions  | 10% | Expert opinion (GOSH, 2015; NORCHI, 2016)[[3](#_ENREF_3),[4](#_ENREF_4)] |
| Annual number of diabetes admissions (excluding hypoglycaemic episode admission)  | 0 | Expert opinion (NORCHI), 2016[[4](#_ENREF_4)] |
| Annual incidence of severe hypoglycaemic events | 0.1150 | Cummins, 2010[[9](#_ENREF_9)] |
| Follow-up visits for all patients |
| Annual number of follow-up visits for CHI patients who are diagnosed and treated successfully with first-line therapy and discharged | 1 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of follow-up visits for CHI patients with focal disease, post-surgery  | 1 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of follow-up visits for medically managed CHI patients with diffuse disease | 3 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of follow-up visits for surgically managed CHI patients with diffuse disease | 3 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Annual number of follow-up visits for CHI patients on sirolimus treatment | 3 | Expert opinion (GOSH), 2015[[3](#_ENREF_3)] |
| Proportion of CHI patients receiving cognitive assessments | 33% | Expert opinion (GOSH, 2015; NORCHI, 2016)[[3](#_ENREF_3),[4](#_ENREF_4)] |

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