Integrated Impact Assessment Report for Service specifications

Reference			
Title	Rare Hereditary Neuropathies For Children and Young People		
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Activity Impact			
Theme	**Questions**		**Comments** (Include source of information and details of assumptions made and any issues with the data)
K1 Current Patient Population & Demography / Growth	K 1.1 What is the prevalence of the disease/condition?		K1.1 The minimal prevalence of hereditary peripheral neuropathies is 11 per 100,000 in Northern England across all ages. Figures as high 40-80 per 100, 000 have been quoted in other papers. The minimal estimated total number of patients with hereditary peripheral neuropathies in England (population of 53 million) is 6300. This includes the

		four common gene mutations plus the rare ones.
	K1.2 What is the number of patients eligible for this treatment under currently routinely commissioned care arrangements?	K1.2 The service provider units will be for the rare hereditary neuropathies which may account for 10% of the total, which gives an overall population of 630 patients, of which the paediatric population is expected to be some 50% or 300 patients in total.
	K1.3 What age group is the treatment indicated for?	K1.3 0-21
	K1.4 Describe the age distribution of the patient population taking up treatment?	K1.4 0-21
	K1.5What is the current activity associated with currently routinely commissioned care for this group?	K1.5 100 new patients, with yearly follow up and associated diagnostic tests, orthotics, physiotherapy.
	K1.6 What is the projected growth of the disease/condition prevalence (prior to applying the new policy) in 2, 5, and 10 years	K1.6 The minimal prevalence of hereditary peripheral neuropathies is 11 per 100,000 in Northern England across all ages.
	K1.7 What is the associated projected growth in activity (prior to applying the new policy) in 2,5 and	K1.7 Activity will be static except for a small level of demographic growth.

	10 years K1.8 How is the population currently distributed geographically?	 K1.8 Related to population, not other factors known.
K2 Future Patient Population & Demography	K2.1 Does the new service specification: move to a non-routine commissioning position / substitute a currently routinely commissioned treatment / expand or restrict an existing treatment threshold / add an additional line / stage of treatment / other? K2.2 Please describe any factors likely to affect growth in the patient population for this intervention (e.g. increased disease prevalence, increased survival) K 2.3 Are there likely to be changes in geography/demography of the patient population and would this impact on activity/outcomes? If yes, provide details K2.4 What is the resulting expected net increase or decrease in the number of patients who will access the treatment per year in year 2, 5 and 10?	K2.1 The activity levels will not be too dissimilar, the way the treatment will be delivered will be quite different, given more robust MDT approach and full diagnostic testing. K2.2 Early diagnosis and treatment plan does increase better quality K2.3 No K2.4 At present this is difficult to quantify as early diagnosis reduces the need for long term treatment and improved outcomes, although early diagnosis and increased awareness of the conditions will mean that cases are identified earlier, which may result in a small increase in numbers each year.
K3 Activity	K3.1 What is the current annual activity for the	K3.1 36 new and 150 follow up patients

	target population covered under the new service specification? Please provide details in accompanying excel sheet	are seen per year in paediatric neurology clinics in specialist provider clinics with follow ups seen twice per year.
	K3.2 What will be the new activity should the new / revised service specification be implemented in the target population? Please provide details in accompanying excel sheet	K3.2 100 news and 300 follow ups per year
	K3.3 What will be the comparative activity for the 'Next Best Alternative' or 'Do Nothing' comparator if the service specification is not adopted? Please details in accompanying excel sheet	K3.3 Same as now – 36 new and 150 follow ups (the difference being patients seen in District General Hospitals who are not being referred and not being identified as possibles).
K4 Existing Patient Pathway	K4.1 If there is a relevant currently routinely commissioned treatment, what is the current patient pathway? Describe or include a figure to outline associated activity.	K4.1 There is no existing formalised pathway that is commissioned.
	K4.2 What are the current treatment access criteria?	K4.2 Referred in by local, or via GOSH neuromuscular service as requiring additional specialist assessment and where basic genetic tests for RHN are inconclusive.
	K4.3What are the current treatment stopping points?	K4.3 Stopping points are: • Patient moves house,

		• Patient is not able to tolerate treatment and a change to the management plan is required (eg comorbidities eg respiratory issues) • Patient moves up to the adult service.
K5 Comparator (next best alternative treatment) Patient Pathway	K5.1 If there is a 'next best' alternative routinely commissioned treatment what is the current patient pathway? Describe or include a figure to outline associated activity. K5.2 Where there are different stopping points on the pathway please indicate how many patients out of the number starting the pathway would be expected to finish at each point (e.g. expected number dropping out due to side effects of drug, or number who don't continue to treatment after having test to determine likely success). If possible please indicate likely outcome for patient at each stopping point.	K5.1 No but some activity does take place now in paediatric neurology and transition clinics in specialist provider clinics with follow ups seen twice, although this is not the same quality of assessment and management that is required and would be provided if the national service was in place. K5.2 This is expected to be small in number. • Patient is not able to tolerate treatment and a change to the management plan is required (eg comorbidities eg respiratory issues) • Patient moves up to the adult service.
K6 New Patient Pathway	K6.1 Describe or include a figure to outline associated activity with the patient pathway for the proposed new service specification K6.2 Where there are different stopping points on the pathway please indicate how many patients out	K6.1 100 new and 300 follow ups per annum. K6.2 Not known

	of the number starting the pathway would be expected to finish at each point (e.g. expected number dropping out due to side effects of drug, or number who don't continue to treatment after having test to determine likely success). If possible please indicate likely outcome for patient at each stopping point.	
K7 Treatment Setting	K7.1How is this treatment delivered to the patient?	K7.1 Acute Trust: Inpatient **Possible** Outpatient **Yes** Mental Health Provider: Inpatient **No** Outpatient **No** Community setting: **Yes** Homecare delivery: Not normally (but local services may provide respiratory support for those patients who may need home ventilation aid (NIV)- but that would be outwith this specification and contract.
	K7.2 Is there likely to be a change in delivery setting or capacity requirements, if so what? *e.g. service capacity*	K7.2 No expected change in delivery setting

K8 Coding	K9.1 In which datasets (e.g. SUS/central data collections etc.) will activity related to the new patient pathway be recorded? K8.2 How will this activity related to the new patient pathway be identified?(e.g. ICD10 codes/procedure codes)	K8.1 SUS K8.2 Procedure codes
K9 Monitoring	K9.1 Do any new or revised requirements need to be included in the NHS Standard Contract Information Schedule? If so, these must be communicated to CTownley@nhs.net, ideally by end of October to inform following year's contract K9.2 If this treatment is a drug, what pharmacy monitoring is required? K9.3 What analytical information /monitoring/ reporting is required? K9.4 What contract monitoring is required by supplier managers? What changes need to be in place? K9.5 Is there inked information required to complete quality dashboards and if so is it being incorporated into routine performance monitoring?	K9.1 This can only be answered as part of the procurement process and as part of contracting. K9.2 Standard monitoring via senior pharmacist K9.3 SUS data on outpatient activity including diagnostics K9.4 A bespoke information reporting schedule will be developed to identify outpatient and diagnostic activity. K9.5 No

	K9.6 Are there any directly applicable NICE quality standards that need to be monitored in association with the new service specification? K9.7 Do you anticipate using Blueteq or other equivalent system to guide access to treatment? If so, please outline. *See also linked question in M1 below*	K9.6 The current NICE guidance does not specifically mention standards for RHN patients, but if the service is commissioned these would be developed. (see specification section 4) K9.7 No.
Service Impact		
Theme	**Questions**	**Comments** (Include source of information and details of assumptions made and any issues with the data)
L1 Service Organisation	L1.1 How is this service currently organised (i.e. tertiary centres, networked provision) L1.2 How will the proposed service specification change the way the commissioned service is organised?	L1.1 Tertiary centres L1.2 There will be a highly specialised hub and spoke network of up to four expert centres in England which will provide comprehensive assessment, electrophysiological and genetic diagnosis and management for children and young people who have a suspected Rare Hereditary Neuropathy.
L2 Geography & Access	L2.1 Where do current referrals come from?	L2.1 Trusts without specialist neuromuscular services

	L2.2 Will the new service specification change / restrict / expand the sources of referral?	L2.2 Referrals should still come from the same source, but geographically there may be some changes within the hubs, depending on how quickly the services are developed.
	L2.3 Is the new service specification likely to improve equity of access?	L2.3 Yes
	L2.4 Is the new service specification likely to improve equality of access / outcomes?	L2.4 Yes
L3 Implementation	L3.1 Is there a lead in time required prior to implementation and if so when could implementation be achieved if the service specification is agreed?	L3.1 Yes, will need to get more physiotherapy, admin, Speech and Language Therapy and clinical nurse specialist time to support the Multi-Disciplinary teams. However, this quantum is not hugely significant, so can be achieved fairly quickly.
	L3.2 Is there a change in provider physical infrastructure required?	L3.2 Subject to the outcome of the procurement process.
	L3.3 Is there a change in provider staffing required?	L3.3 Yes to increase the provision of specialist time available to staff clinics, audit, peer review, specialist training

		etc. (see L3.1)
	L3.4 Are there new clinical dependency / adjacency requirements that would need to be in place?	L3.4 Access to psychology services
	L3.5 Are there changes in the support services that need to be in place?	L3.5 Yes, establishing networks to educate and share expertise.
	L3.6 Is there a change in provider / inter-provider governance required? (e.g. ODN arrangements / prime contractor)	L3.6 No
	L3.7 Is there likely to be either an increase or decrease in the number of commissioned providers?	L3.7 None at present so no, it is estimated that there will be up to four new providers, subject to procurement.
	L3.8 How will the revised provision be secured by NHS England as the responsible commissioner (e.g. publication and notification of new policy, competitive selection process to secure revised provider configuration)	L3.8 Subject to procurement.
L4 Collaborative Commissioning	L4.1 Is this service currently subject to or planned for collaborative commissioning arrangements? (e.g. future CCG lead, devolved commissioning arrangements)?	L4.1 No
Section M - Finance Impact		

Theme	**Questions**	**Comments** (Include source of information and details of assumptions made and any issues with the data)
M1 Tariff	M1.1 Is this treatment paid under a national prices*, and if so which?	M1.1 Local tariffs
	M1.2 Is this treatment excluded from national prices?	M1.2 Yes
	M1.3 Is this covered under a local price arrangements (if so state range), and if so are you confident that the costs are not also attributable to other clinical services?	M1.3 Yes, local tariff for neuromuscular patients one of which is circa £2000 for a new and around £500 for a follow up.
	M1.4 If a new price has been proposed how has this been derived / tested? How will we ensure that associated activity is not additionally / double charged through existing routes	M1.4 Via bottom up costs developed by providers who supply similar services.
	M1.5 is VAT payable (Y/N) and if so has it been included in the costings?	M1.5 No
	M1.6 Do you envisage a prior approval / funding authorisation being required to support implementation of the new service specification?	M1.6 No
M2 Average Cost per Patient	M2.1 What is the revenue cost per patient in year 1?	M2.1 £3800- £5,000 (includes Outpatient assessment + diagnostics)
		M2.2 £2900- £4,100 (includes OPA +

	M2.2 What is the revenue cost per patient in future years (including follow up)?	diagnostics)
M3 Overall Cost Impact of this Policy to NHS England	M3.1 Indicate whether this is cost saving, neutral, or cost pressure to NHS England? M3.2 Where this has not been identified, set out the reasons why this cannot be measured?	M3.1 There will be additional costs relating to specialist staffing. M3.2 Costing are based on current provider activity and the specification outlines additional responsibilities for MDTs and Lead hubs, which don't currently exist.
M4 Overall cost impact of this policy to the NHS as a whole	M4.1 Indicate whether this is cost saving, neutral, or cost saving for other parts of the NHS (e.g. providers, CCGs) M4.2 Indicate whether this is cost saving, neutral, or cost pressure to the NHS as a whole? M4.3 Where this has not been identified, set out the reasons why this cannot be measured? M4.4 Are there likely to be any costs or savings for non NHS commissioners / public sector funders?	M4.1 Small additional cost as there will be an offset against current cost of these patients who are seen primarily in tertiary paediatric neurology clinics but without the level of dedicated multi-disciplinary clinician time. M4.2 Cost pressure M4.3 It can be measured. M4.4 No
M5 Funding	M5.1 Where a cost pressure is indicated, state known source of funds for investment, where identified	*M5.1 2016/17 Prioritisation monies, although it is likely that the cost to the NHS will be offset by a small reduction in activity currently taking place in specialist tertiary units.*

M6 Financial Risks Associated with Implementing this Policy	M6.1 What are the material financial risks to implementing this policy? M6.2 Can these be mitigated, if so how? M6.3 What scenarios (differential assumptions) have been explicitly tested to generate best case, worst case and most likely total cost scenarios	*M6.1 Low level risk due to the number of patients involved.* *M6.2 Monitoring activity in year one and establishing trends, appropriateness of referrals.* *M6.3 None*
M7 Value for Money	M7.1 What evidence is available that the treatment is cost effective? M7.2 What issues or risks are associated with this assessment?	M7.1 Clinical trials, muscular dystrophy campaign member feedback M7.2 Best estimate based on current level of knowledge.
M8 Cost Profile	M8.1 Are there non-recurrent capital or revenue costs associated with this service specification M8.2 If so, confirm the source of funds to meet these costs.	M8.1 Yes – around £15,000 per provider site x 4 = £60,000 plus VAT for gait assessment equipment. *M8.2 2016/17 Prioritisation Monies*