Multiple Sclerosis Management for Children Service
Appendix One – Stakeholder/CRG Feedback

Organisation Responding	Feedback Received	PWG response	Resulting Action
Penny Gray for Paediatric Neurosciences CRG	Concern re assumptions about ODNs which are not consistent [in form] across the country and many are neurosurgical, not neuroscience networks, the concern being that the pathways may not be in place or that networks may not have the ability or capacity or remit to establish networks. Concern re assumptions as to what the spokes will be expected to deliver (e.g. links to CAMHS) as this isn't part of the current neurology specification. Referrals most likely to come from tertiary referral centres. Concern that there is a risk that all activity will flow to the Hub even if this isn't the intention – or NHS England may have to pay both Hubs and Spokes for the same activity. The impact report reference to the survey undertaken in 2014 (A1.5 page 2) should note that 12 centres responded to the survey. There are no designated paediatric neurosciences centres, rather there are a number of centres across the country which provide paediatric neurology services.	The references to working with ODNs will be removed; the naming of the national centres as Hubs will be retained but the terminology for provider units which refer to the Hubs will be changed to 'referring' units; the SWG confirmed that no additional actions as compared to now will be placed on referring units and this will be made clear in the document; the Hubs will produce a single set of referral guidelines to aid referring centres in making high quality referrals including appropriate diagnostics* as the key potential duplication would be in radiological investigations. The UK	Amends made to document: • ODN references removed • Word 'Spoke' to be changed to 'referring' unit • Wording in the impact document changed to show that there were 12 responses to the 2014 survey.

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		Childhood Inflammatory Disorders (UKCID) is currently working to standardise imaging protocols across all sites looking after children with brain inflammation which will significantly limit the need for repeat investigations. The standardised clinical and investigative pathway will mean that all results performed at both Hubs and referring units will be comparable and will not need repeating. As such, we anticipate where there is suboptimal imaging or where there are equivocal results will investigations need to be repeated.	
Metabolic CRG	Just to confirm that the Metabolic CRG had no comments in relation to this service specification.	The SWG noted this.	No changes required.
Dan Rattigan, MS Society	We broadly welcome the development of a service spec – it aims to provide age appropriate specialist care, in a hub and spoke model with access to an MDT, with considered transition to adult services when appropriate, all of which seem ‘good’ things We also welcome focus on access to treatments –	The SWG noted these comments and are continuing dialogue with eth MS Society on these matters, although no change to the specification is	No change required

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	however note this must link to forthcoming DMT algorithm It's good that local services will be able to refer into the specialist hubs – it's important that there is communication between these component parts to ensure that there is no fragmentation for the patient We welcome the focus on ensuring that people can receive support as close to home as possible – this is important, given the relatively small number of hubs proposed I think the development of a national database of treatment and outcomes sounds really exciting It's also going to be important for communication of the specialist team with services outside of the specialist care they receive (for example a school) to ensure they are able to make adjustments etc as necessary	needed as such.	
Linden Muirhead MS Trust	The MS Trust welcomes the opportunity to respond to this service specification, and will take account of the final version within our information resources. Within this consultation it will be important to help service users to fully understand the hub and spoke model, the benefits and what it will mean from a practical perspective. We would be happy to support this engagement activity as appropriate. Specifically, we are concerned that three hubs across the country could place additional pressure on families by creating the need for frequent travel to access appropriate care and the time taken away from work (parents) and education. We would welcome consideration of greater delegation to local/spoke services for the ongoing management, post diagnosis and	The SWG noted that the three Hub Lead Centres were designed to be based around major population areas, and that the model of care of shared care with referring units will enable children to be treated appropriately closer to home once initial diagnosis and care planning has been undertaken. Most patients (75%) are likely to have low levels of need Tier 1 or tier 2	Shared care model emphasised in specification. Wording changed Change to wording on page 3, as follows: 'agree standardised minimum data set on treatment and outcomes which will feed into national

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	treatment pathway. We are keen that this specification is considered alongside other paediatric and adult MS services, to ensure holistic care and effective transition at the appropriate time. This could form part of the consultation process. We provide information and an enquiry service to support people affected by MS and are in the process of developing resources designed with and for teenagers. In a recent evaluation of our information and enquiry services, it was confirmed that people with MS often use our services when they are unable to access specialist healthcare. We therefore see that we provide vital services that complement the clinical management of MS in both adults and children and with the hub and spoke model, can provide additional resources for people to access. We have given below two specific examples of where this information could be included within the specification but would welcome any changes throughout which reflect this additional support. We welcome the use of an MDT at the hub centres. At the local level, this model could also apply with the wider involvement of AHPs to aid relapse therapies.	(20%), with only a very small number requiring ongoing treatment and review due to the severity of their condition (Tiers 3 and 4). The model of care will enable referring units to provide higher quality care to patients through the provision of expert care planning, advice as required, standardised clinical guidelines and support for participation in clinical trials as appropriate. NICE guidelines on transition will be followed, transition will be managed with the support of adult MS experts, appropriate supporting documentation will be developed and patients will be transitioned to the most appropriate local adult unit.	databases, ensuring that patient confidentiality is maintained and consent secured. These data will also feed into the national Multiple Sclerosis Register'. This was clarified in the specification Tier 3 p) and q). Wording on page 8 changed to reflect this. Wording on page 8 changed to reflect this.
	2.1 Care Pathway, item iii makes mention of developing a national database. Is this proposal just for patients with paediatric onset MS, or is it linked to the national MS	The SWG noted that data collection will be developed/aligned in	Wording changed to note: 'Database will feed into/ be

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	register in some way? Particular care will need to be taken in terms of the personal data of minors.	conjunction with national databases, making sure that patient confidentiality is maintained and consent given as required and will be part of the national Multiple Sclerosis register.	linked to MS Register. Wording amended accordingly'.
	Tiered model of care, Tier 3, items p) and q) are slightly contradictory. If spoke / local units cannot prescribe specialist MS medications, yet hubs prescribe for highly active MS and infusions, what about injectables or oral drugs for active MS?	The SWG noted this comment and gave the following response: 'as now, first line disease modifying drugs would continue to be prescribed by spoke units, although drugs for highly active second line will be prescribed at a Hub to ensure that specialist management is undertaken of impacts of this treatment and its side effects'.	Wording amended to clarify this.
	2.2 Interdependence with other Services makes mention of Third Sector services to support adherence, peer support and self-management programmes. We believe there is a place for age appropriate information resources to improve knowledge and understanding, and to build confidence that aids shared decision making and would	The SWG noted this comment. Wording to be changed to note that information needs to be age appropriate.	Wording changed to align to this.

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	like to see this reflected here. Similarly, in the para below, where the Local Authorities example is given, we would also wish to see Third Sector organisations mentioned as a source for information and support.	The SWG noted this comment	Wording was changed to align to this.
British Paediatric Neurosciences Association (BPNA)	Previously submitted (Dec 2016): The BPNA is wholly behind this initiative on Multiple Sclerosis in children and very much looks forward to contributing to the remaining stages of the programme to establish national commissions,	SWG noted this comment.	No changes required.
Epilepsy UK	No response received	No comment required	No changes required.
Together for Short Lives v	No response received		No changes required.
Muscular Dystrophy UK	No response received		No changes required.
Juliet Brown Midlands Children's Neurosciences Network	1. This proposal will improve the care of children with relapsing demyelination. a. Improvement of the diagnosis and the patient experience e.g. investigations will be tailored. b. A smooth treatment pathway leading to less hospital admissions, good school attendance and better quality of life. 2. The proposed Hub and Spoke Model educates, enhances local skills and promote excellent care for	The SWG noted these comments	No changes required.

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	children throughout the UK. It promotes more joint up working and allow a smooth transition back to adult service when the child reaches adulthood.		
Stefano Seri Birmingham Women and Childrens NHSFT	A serious omission in the expertise required/expected to support the service. Clinical Neurophysiology (Nerve Conduction studies as well as multimodality Evoked potentials, particularly the visual modality) is a crucial part of non-invasive monitoring and early diagnosis, particularly for Optic Neuritis. This can be diagnosed early when waiting times for MRI can be long. There is in my opinion a legitimate expectation that expertise in paediatric clinical neurophysiology is included in the specifications.	The SWG noted this oversight and will add into the document. The need for expertise in clinical neurophysiological studies is recognised. Add in to specification (section 2.1) which may be provided by a clinical neurophysiology or ophthalmology department yes see 2.1 pg 4 oitem 4	This has been added into the document.
RCPCH	The RCPCH welcomes the opportunity to respond to the consultation on the Multiple Sclerosis Service Specification for management in Children. We have liaised with the Neurology and Neuro-disability Sub-Specialty Groups within and linked to the College and have responses from the British Paediatric Neurology Association (BPNA) and the British Academy of Childhood Disability (BACD) who made the following points: The process of development of this specification has been one of co-production with patient representatives, which is very welcome. The specification is sensible in its approach and we are keen to support this initiative for the	The SWG noted the comments and proposed to add additional wording to the specification to emphasise the need for early referral and assessment.	Specification wording changed to reflect this point in section 1.2 which now has the additional wording: 'There is a particular need focus on the early recognition of these serious neuro-inflammatory

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	management of inflammatory white matter disorders and other related CNS inflammatory disorders. Given the improvements in terms of lasting induction of remission with early intervention the Commissioners should particularly emphasise the need for early intervention, including intervention in young or very young children where indicated. A focus on early recognition of these serious neuro-inflammatory disorders is therefore essential to reduce long-term morbidity and neuro-disability.		disorders to reduce long-term morbidity and neuro-disability and for early intervention, including for young or very young children where indicated'.
Jacqueline Palace, NMO service, Oxford	I note that the application for a specialist service in MS in children but this also MOG and AQP4 ab disease. In fact this will not be rare in children if all these conditions are together (MOG is common in children – in half of ADEM patients). Also there already is a specialised service with clinics in NMO covering children with paediatric cases covered in Oxford Liverpool and London (GOSH) won't this be a duplication? MS alone is probably rare but not with all other demyelinating condition?	The SWG noted: 'We had assumed it was explicit in the proposal that the plan was to work in conjunction with the NMO service for the range of conditions where there is an overlap (See Scope Section 1.2). This will be added this to the Figure of the service to highlight this. Patients with NMOSD will be managed in the NMO service. Notably, this proposed service working in conjunction with the NMO service will increase the accessibility of specialists and up-skill more centres in providing the care for these	Added into specification that all children with NMOSD will be seen jointly with the NMO service (page 1). Additional wording re joint clinics to added into pathway map on page 8.

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		children more locally (see point raised by RCP). The current NMO service is for patients with NMOSD and not for Paediatric MS and relapsing MOG and other relapsing Central Nervous System demyelinating disorders. This proposed service will complement the current NMO service for patients with relapsing demyelination syndromes that are not NMOSD (Paediatric MS, relapsing MOG and other relapsing CNS demyelinating disorders).	
RCP/ Dr Andrew Goddard	The RCP is grateful for the opportunity to respond to the above consultation. We have liaised with our Young Adult and Adolescent Steering Group and would like to make the following comments. MOG and AQP4 antibody disease are not rare diseases and most of the big centres are able to see and deal with these children (in a national service for MOG and AQP4 currently which includes children). We are concerned that if these are included with MS children will often have to travel to see the expert. Our experts note that schooling children and parents prefer to be seen locally and this	The SWG acknowledged the concerns raised by the RCP and noted that in planning this service proposal, the consideration was to balance the provision of accessible service locations with access to an expert team which sees enough patients to have the appropriate expertise.	Added into specification that all children with NMOSD will be seen jointly with the NMO service (page 1). Additional wording re joint clinics to added into pathway map on

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	would deskill local services. Where a disease is common in adults, spreading the funds across more sites and encouraging a local paediatric neurologist to see such children in the presence of the expert adult neurologist would grow the local expertise and resources and be more accessible to children. This also allows long term relationships and transition because the child would know the adult service teams. This is better than travelling to one of three centres then going to a different centre at the age of 16. Our experts suggest a twelve England site service with resources split for MS.	Shared care between referring tertiary and the national Hub Lead Centres will provide the required balance. ii) The SWG notes that the numbers are very small, with a) relapsing MOG and AQP4 disease, a focus of the proposed MS service, being uncommon in children, as evidenced in published work from the UK (NMO service and UKCID investigators), b) anticipates that only 80 children with relapsing demyelination will be identified per year in the UK c) there are currently less than 10 children in England seen by three of the four units which have supported the development of this specification d) AQP4 disease is also rare, of which 30 patients will have non-MS demyelination e) even accounting for accrual of patients, the prevalence	page 8.

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		is unlikely to be more than 150 in UK. Hence, the model proposed for three Hub Lead Centres working with their referring units will provide better access to specialist care and will serve to make sure all units can deliver a higher standard of care for patients with inflammation. Currently NMO/AQP4 disease patients are served by the Highly Specialised NMO service in Oxford and Liverpool; see later section on how we plan to work with NMO service). Importantly, here in this service proposal, we also take into account of how we transition children back to the local (or most appropriate) adult MS or NMO service.	
Dr Chow, Nottingham University Hospitals NHS Trust	We have a large adult MS service here so transition should transfer adults back to care in Nottingham. The over plan is excellent. I think potential for involvement in clinical research, and service evaluation and clinical audit / Quality improvement should be built in as expected for	The SWG noted this and commented: We strongly agree with this point and the service will seek to identify the local or the most	Wording changed in Section 1.5 page 2 to reflect this.

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	all patients.	appropriate adult service for transition of care.	
Dr WP Whitehouse, Nottingham University Hospitals NHS Trust	It would help to have a summary or executive summary: one side A4. With respect to transition, the services for adults with ADS and MS are much more developed and the numbers much greater so the adult service they transition to should be more local. For example a child with MS in Nottingham, managed primarily by the Hub in Birmingham, should be transitioned to the adult MS service in Nottingham. The over plan is excellent. I think potential for involvement in clinical research, and service evaluation and clinical audit / Quality improvement should be built in as expected for all patients.	The SWG noted this and commented: We strongly agree with this point and the service will seek to identify the local or the most appropriate adult service for transition of care.	Wording changed in Section 1.5 page 2 to reflect this.
Dr Kate Scarff (Paediatric Neuropsychologist and Lead for Paediatric Neuropsychology, The John Radcliffe Hospital) and Dr Stephanie Satariano (Educational Psychologist in Neuropsychology)	We would be supportive of this specialist service model for this group of patients, enabling better access to experts in the area and ensuring equity of access to specialist care, whilst enabling care of children to be provided as close to home as possible. Psychological expertise in the Hub centres is referred to by different terms throughout the document. We strongly recommend that given the nature of the conditions and the expertise required that this should state 'neuropsychologists' rather than clinical psychologists. Given the expertise required in these roles we would suggest that at the Hub Centres this should be a senior/consultant neuropsychologist, preferably with the Qualification in Clinical Neuropsychology. The psychology support for Tier 1 – Tier 4 patients is confused. We would recommend that in the Hub centre	SWG noted these comments and agreed to change wording to 'clinical psychology, and if required a neuro psychologist'. Noted re role of Hub psychologists – this will be added in.	Document amended to read 'clinical psychology, and if required an neuro psychology support'. The role of the Hub Centre psychology/ neuropsychology team has been clarified at Tiers 3 and 4. Wording on

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	neuropsychologists maintain expertise in MS and ADS conditions, identify appropriate and consistent neurocognitive, emotional and behavioural assessment protocols, and provide advice to local services about the assessment and follow-up of patients. They would also take a role in research and contribute to knowledge about outcomes. Family and systemic support should also be highlighted. Local/Spoke units would provide psychology, most likely through tertiary neuropsychology services requesting input from liaison psychiatry, paediatric psychology and CAMHS services as appropriate. There needs to be greater clarity about the provision of educational liaison through the Spoke/Local units. Specifically, it should be stated that there needs to be on-going communication between health and educational services (through identified lead workers), as well as training and education to schools on child specific needs. Health and education should link up through MDT meetings from the outset, so as to maximise the transfer of expertise to education staff who will have on-going involvement with the child. It should also be specified that neuropsychology would link up with the local schools and educational psychology. An Education, Health and Care (EHC) profile should be started (if appropriate), particularly in light of the valuable on-going MDT support, that will provide valuable information to the process. Furthermore, the suitability of school placement should be considered, should there be a significant change in needs		educational liaison included. EHC process included. Added in: 'The Clinical nurse specialist as well as the clinical psychologists/ neuropsychologist will manage situations such as school avoidance, depression, anxiety needle phobia, adjustment disorder. The educational psychologist or neuropsychologist will assess cognition and advise the local education authority.

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	post-illness. It is also likely that during illness such children will miss significant amount of school; thus this needs to be address once they are able to. It was not clear which third sector services were being referred to that support adherence, peer support and self-management programmes. We were unsure what has led to the specification of 3 Hub centres, but wondered whether this is a sufficient number. We support the point about the need to think about and plan transition in a timely way, but there needs to be more explanation about how this will occur. The Education, Health and Care process uses person centre planning principles which would act as a good template.		
Juliet Brown, West Midlands Neurosciences Network	In support, no issues	SWG noted this	No amendments required.
Fiona Reynolds Birmingham Women and Childrens Hospital	In support of the document	SWG noted this	No amendments required.
Novartis Pharmaceuticals Ltd is the Marketing Authorisation Holder of	Novartis welcomes the opportunity to respond to the proposed updated service specification for MS Management Service for Children. We are supportive of the intent to provide access to the right medicines and services for children with MS or 'MS-like' demyelinating syndromes. There is a clear focus to ensure: All eligible	The SWG noted these comments. The Hub and referring unit model, with its two way communication, clinical guidelines, advice and	Reflect in the specification: Hubs will support the undertaking of clinical trials in referring centres

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Gilenya (fingolimod).	patients will have early access to care; Appropriate transition from paediatric services to adult services; Multi-disciplinary team decision making. General The proposed hub and spoke model of care to be delivered through three 'Hub' Lead Centres based in the North, Middle and South of England has been proposed to provide a service network across the country, however we are concerned that this may not be adequate and propose this is increased to 4 lead centres in order to minimize impact on patients and their carers/parents– in terms of travel times and potential disruption to education. It is also clear that key treatment decisions for paediatric MS patients would largely be determined by just three hub lead centres in England as described in the "four tiers" of care. This could potentially impact patient access for both diagnosis and ongoing reviews and management of relapses. The responsibility for treatment decisions for DMTs [disease modifying treatments] would also be largely determined by these three centres, which could be restrictive in terms of patient therapy management. This model is also largely dependent upon the referral pathways being clearly defined and adopted to ensure patients can move through the pathway without delay and disruption. We are in agreement with the proposal that lead centres are selected based on expertise and that spokes will become part of an existing paediatric delivery network,	support will enable patient care and treatment, including clinical trials to occur on a shared care basis and will be focussed on more than the three national centres, thereby improving the quality of life for patients and their carers/parents in terms of travel times and potential disruption to education. Centres which deliver treatments through a clinical trial have to have appropriate expertise and experience with this patient population. Those units which, after discussion with the Hubs feel that they have the necessary patient population and appropriate resources to undertake a trial appropriately may do so. The Hub units would offer any support necessary. Regarding the number of Clinical Nurse Specialists,	which, following discussion, have the necessary patient population and appropriate resources to undertake a trial appropriately.

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	thereby building on and improving existing infrastructure and services This would ensure paediatric patients receive the best possible care which is standardized across the country. The suggested minimum of one designated nurse specialist in each hub plus 'cross-cover' may not be sufficient based on the wide geographical coverage of the hub lead centres. The four tiers of care have clearly defined roles and responsibilities- with the most serious patients having their diagnosis and the majority of their care under tier levels 3 and 4. We are supportive of the additional layers of support and care offered to patients as the severity of their condition increases, however the roles and responsibilities will need to be clearly defined and agreed as these services are implemented to ensure minimal disruption to patient care. We would be interested to understand how these services are going to be monitored and audited to demonstrate that patients are being diagnosed earlier and that they have access to appropriate treatments to improve their long term outcomes.	one per Hub unit will be adequate.	
Dr Emily Talbot, Consultant Clinical Psychologist in Paediatric Neuropsychology,	On reviewing the proposed service specifications the proposals look generally very good. Though we have observed some inconsistencies in reference to psychological support. Reference is made to input from clinical psychology and educational psychology within the lead Hub centres, however, there is no specific reference to Paediatric Neuropsychology. Neuropsychologists may	SWG noted these comments and agreed to clarify nature of support including onward referral to neuropsychologists.	Neuropsychology added into the specification as suggested.

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Nottingham University Hospitals NHS Trust.	be Clinical Psychologists or Educational psychologists who have completed further training in neuropsychology. It would be important in any documentation to ensure that neuropsychology is included. Generally there may be general paediatric Clinical Psychology services available within the hospital services as well as Paediatric Neuropsychology in some. Educational Psychology services would generally be provided through schools/local education authorities. For example, within our hospital – which is a regional neurosciences unit – we provide paediatric neuropsychology which would see children (such as those with ADEM, MS etc) for cognitive assessment, which would include liaison with schools to offer support and recommendations regarding educational support based on cognitive difficulties as a result of their neurological condition) but there would also be Educational psychology services within the local education authority attached to schools who may be included to support within the school system. In addition we also have general paediatric Clinical Psychology services (although within our hospital this is a very limited service) who may see children for ongoing therapeutic support/advice regarding mood, behaviour etc. As well as then potential referral on to CAMHS if needed. So where the document makes reference to the Hub lead centre educational psychology team (e.g. page 5 – tier 2 point i) – this should be Paediatric neuropsychology Team as in our experience there would not be a specific educational psychology team within a hospital setting (though the		

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	paediatric neuropsychology service may be made up of neuropsychologists, clinical psychologists and/or educational psychologists dependent on their routes into the profession and stage of training). Also page 4, point 3) refers to access to neuropsychology (clinical and educational) – this may be better referred to as Paediatric Neuropsychology. On page 3 in the first paragraph it makes reference to clinical psychologist input to the MDT and would be important to include paediatric neuropsychology.		