CLINICAL PRIORITIES ADVISORY GROUP
08 January 2020

Agenda Item No	
National Programme	Women & Children
Clinical Reference Group	Paediatric Neurosciences
URN	1662

Title
Paediatric Neurosciences: Inherited White Matter Disorders Diagnostic and Management Service (IWMD) (All Ages)

Actions Requested	1. Agree the Service Specification Proposition

Proposition
The proposal is to routinely commission the provision of an Inherited White Matter Disorders (IWMD) Diagnostic and Management Service for all ages. The service will support local neurology services to provide diagnosis and management in their locality for the majority of patients, by providing expert opinion on existing test results and a care plan; provide clinical guidance that additional assessments are required to be undertaken locally and where diagnostic uncertainty remains, assess a small number of patients face to face and create bespoke care plans for local delivery in a shared model of care. Genetic testing of siblings in diagnosed cases will also take place. A financial review has been carried out and it is confirmed that the service specification does not propose any change to the way activity is charged or recorded or the responsible commissioner.
Clinical Panel recommendation
Not applicable.

The committee is asked to receive the following assurance:	
1.	The Head of Clinical Effectiveness confirms the proposal has completed the appropriate sequence of governance steps.
2.	The Head of Acute Programmes confirms the proposal is supported by an: Impact Assessment; Stakeholder Engagement Report; Consultation Report; Equality Impact and Assessment Report; Service specification. The relevant National Programme of Care has approved these reports.

3.	The Director of Finance (Specialised Commissioning) confirms that the impact assessment has reasonably estimated a) the incremental cost and b) the budget impact of the proposal.
4.	The Operational Delivery Director (Specialised Commissioning) confirms that the service and operational impacts have been completed.
5.	The Head of Quality Assurance (Specialised Commissioning) confirms that the proposed quality indicators have been adequately defined.

The following documents are included (others available on request):	
1.	Service Specification Proposition
2.	Stakeholder Testing Report
3.	Evidence Summary (where completed) - not applicable
4.	Clinical Panel Report (where completed) - not applicable
5.	Equality Impact and Assessment Report

No	*Metric*	*Summary of benefit (where applicable)*
1.	Survival	
2.	Progression free survival	
3.	Mobility	
4.	Self-care	
5.	Usual activities	
6.	Pain	
7.	Anxiety / Depression	
8.	Replacement of more toxic treatment	
9.	Dependency on care giver / supporting independence	
10.	Safety	

11.	Delivery of intervention	

No	Metric	Summary from evidence review

Considerations from review by the Rare Disease Advisory Group
RDAG endorsed the specification proposition and model of care in January 2019.

Pharmaceutical considerations
Not applicable.

Considerations from review by National Programme of Care
POC Board support: 1) The Proposition received the full support of the Women and Children Programme of Care Board in April 2019. 2) The May 2019 Patient and Public Voice Advisory Group confirmed that the specification proposition had had sufficient engagement given the significant engagement that had taken place with stakeholder groups and clinical groups since 2016 and taking into account the non-material nature of the comments received as part of stakeholder testing. 3) The proposition received the full support of the Rare Disease Advisory Group in July 2019. **Benefit of Service Specification:** The material benefits that patients will receive following the adoption and implementation of this specification are added value to the patient's pathway as the service will greatly accelerate the rate of early diagnosis and optimal management and prognostic advice; it will provide advice on the management of co-morbidities; appropriate genetic counselling and life-planning (carrier testing, reproductive choice); ensure the initiation of treatment or early participation in a therapeutic trial (when available) and, timely engagement with local palliative care services to ensure good quality end of life care as appropriate. In most cases, due to the three levels of care model which is based on need, most patients will not need to travel as the care pathway will inform, enable and support local neurologists to provide better care locally. This will be enabled by a new virtual MDT at each of five designated centres three for the Paediatric service and two for the adult service.

There are a number of therapeutic products being developed which are in scope for leukodystrophy diseases. In the event that such products are commissioned, a commissioned service would support the delivery of such treatments.

Implementation timescale:

Provider selection process required. Expected implementation date is 01 April 2020.