

February 2016

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Accordion:

Leeds Teaching Hospitals NHS Trust

Project name: Leeds Children's Hospital (Leeds Teaching Hospitals NHS Trust)
Paediatric Haemoglobinopathy service development.

Project period: 24 months

Joint working project summary: Novartis to work in partnership with Leeds Children's hospital to improve the quality and governance of the clinical service in Leeds for paediatric haemoglobinopathy patients across Leeds and the surrounding areas:

- To improve the transition from paediatric to adult services, by establishing a clear and practical transition pathway, and regular meetings between the funded paediatric haemoglobinopathy nurse with the adult haemoglobinopathy nurse.
- To increase the regional network links by expanding the regional case/service review meetings to include Dewsbury and Calderdale.
- To deliver patient and family education to support improved health knowledge of parents and their children improving patients compliance with treatment and patient outcomes.
- To set up a patient service evaluation audit to evaluate the current service and identify any future service development to better meet patient needs.
- To deliver additional audits required to meet national standards and peer review. (Penicillin prophylaxis, Immunisations, TCD programme, Haemoglobinopathy registry, Transfusion programme, Chelation, Annual review.)
- To develop haemoglobinopathy nursing and service guidelines to ensure there is a consistent service in the absence of the lead nurse (annual leave/sickness)

Expected patient outcomes for this project:

- To improve the transition from paediatric to adult services by establishing a clear and practical transition pathway and by ensuring regular meetings between the funded paediatric haemoglobinopathy nurse and the adult haemoglobinopathy nurse.
- Deliver patient and family education to support improved health knowledge of parents and their children, improving patient's compliance with treatment and their treatment outcomes.
- Set up a patient service evaluation audit to evaluate the current service and identify any

future service development which will better meet patients' needs.

- Develop haemoglobinopathy nursing and service guidelines to ensure there is a consistent service in the absence of the lead nurse (annual leave/sickness)

Start Date & Duration: July 2014 – July 2016

Job Bag: EXJ16-C009

Date of Prep: February 2016

Leeds Teaching Hospitals NHS Trust

Project Name: Yorkshire and North Lincolnshire Regional Paediatric Multi-disciplinary TSC Clinic

Project period: 12 months

Joint Working Project Summary:

Leeds Teaching Hospitals and Novartis Pharmaceuticals are working together to create a Multi-disciplinary Tuberous Sclerosis Complex (TSC) Clinic. TSC is a complex multi-organ disease affecting an estimated 170 children in a population of around 5 million within the geographical area of Yorkshire and North Lincolnshire, covered by this proposed clinic. Some of these patients will be undiagnosed. Some of these patients will be known to Leeds Teaching Hospitals NHS Trust ("LTHT"). Children with this condition will range from mild to severely affected in one or more of the body systems. We propose, in line with the proposed National Commissioning Service Specification, to set up a multi-disciplinary regional TSC clinic. We envisage care to be delivered close to patients' homes by local services but with guidance and oversight from the General Infirmary at Leeds.

Expected patient outcomes for this project:

- Patients will receive comprehensive expert examination leading to a detailed bespoke care plan.
- Patients will have a local centre with defined contacts to use first line.
- Patients will have a planned transition to adult services.
- Patients will have access to psychological assessment.

Start Date and duration: February 2016 – February 2017

ONC15-C049b February 2016

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