

April 2016

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Accordion:

Birmingham Children's Hospital NHS Foundation Trust

Project name: Tuberous Sclerosis Complex Clinic (TSC) Joint Working Project

Project period: 12 months

Joint working project summary: The aim of this project is to improve the care of patients in the West Midlands Region with the rare disease TSC. It will provide a specialist one-stop TSC multidisciplinary clinic where children, young people and their families can see all of the specialist clinical teams managing their care within a single visit. A clinical team and specialist nurse already exist but there is a need to expand the team with Psychology and Transition worker input and bring all these specialties into one clinic. In addition to medical complications, TSC is known to be associated with a wide range of cognitive, behavioral and psychiatric manifestations which are often of great concern to individuals with TSC and their families. Psychology input will be a valuable asset to the clinic in addition to the transition worker who will ensure smooth transfer of suitable patients to the adult hospital.

- Expected patient outcomes for this project: It is expected that the TSC clinic will provide:-
- Coordinated care to manage potential complications of TSC and improve clinical outcomes.
- Provide psychological and cognitive screening assessment in clinic(80% of patients assessed by month 8)
- Appropriate transition of TSC patients
- Reduction in Patient's appointment burden
- Improvement in Psychological wellbeing as measured by appropriate tool.
- Improvement in patient satisfaction as measured by Rare Diseases Patient Experiences Survey
- Access to peer support
- Improved Diagnostic Pathway
- Educational programs to patients, families, carers
- A Tuberous Sclerosis Association(TSA) Advisor present in clinic
- Access to all available research and treatment options

Start Date and Duration: April 2016 – April 2017

ONC16-C024a April 2016

St Georges NHS University Hospitals NHS Foundation Trust

Project name: St Georges NHS University Hospitals NHS Foundation Trust (SGUHFT) Tuberous Sclerosis Complex (TSC) Specialist Service Development

Project period: 15 months.

Joint working project summary: Tuberous sclerosis is an exemplar rare disease affecting an estimated 1 in 10,000 births and with a measured prevalence of approximately 1 in 20,000 of the population. People with tuberous sclerosis often have complex care needs, encompassing clinical, psychological, social and educational support. St Georges NHS University Hospitals NHS Foundation Trust (SGUHFT) and Novartis Pharmaceuticals UK Ltd have come together with the aim of developing a focused and patient-centric Tuberous Sclerosis Service that will provide additional resource and the correct expertise and skills to deliver a robust patient pathway, improve the care provided to patients through education and ongoing management of this rare condition; together with a service evaluation.

In order for the Project to achieve this aim, the focus will be on delivering the following objectives:

1. Improvement in the quality of service provided for referred and currently treated TSC patients.

Aim: To develop a service that allows better focus of care for TSC patients and their families from a Multi-Disciplinary Team, via timely reviews (as per Consensus Guidelines) and coordinated nurse supported care which will release Clinical Specialists time and ensure patient attendance at clinics.

2. To ensure patient involvement and engagement in the development of the service.

Aim: To work in partnership with the Tuberous Sclerosis Association (TSA) to ensure patient group representation in service evaluation and that patients' needs are firmly rooted in the development of the service.

3. Formalisation of the Adult and Paediatric TSC specialised service across the Catchment Area.

Aim: To formalise and improve referral, diagnosis and management mechanisms to ensure all TSC patients are referred appropriately, diagnosis confirmed and captured on a database and a costed TSC pathway produced to support long term planned activity for the service.

4. Improvement of access to innovative medicines and treatments for TSC patients across the Catchment Area.

Aim: To have an infrastructure and database in place to ensure St. Georges can participate in more national and local TSC trials/research, as well as collaboration with commissioning organisations and patient support groups, such as the TSA, to improve the availability of currently licensed medicines for deserving TSC patients in order to improve their quality of life and survival.

5. Secure long-term funding from SGUHFT.

Expected patient outcomes for this project:

Improved quality of care, where patients receive a named key worker providing coordinated and complex care at each point along the patient pathway providing support as measured by

patient satisfaction against baseline. Developing and establishing robust patient pathways and improved network referrals. Improved educational support and liaison with the TSA patient group to ensure patients and families are fully equipped to manage their diagnosis and disease. By providing additional nursing support and developing an agile TSC database, patients will benefit from advice and assurance in addition to an improved access for patients to innovative medicines via an effective and efficient database.

Start date and duration: April 2016 – July 2017
ONC16-C011a April 2016

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