Sheffield Children's NHS
NHS Foundation Trust

NHS
Sheffield Teaching Hospitals
NHS Foundation Trust

Western Bank
Sheffield
S10 2TH

www.sheffieldchildrens.nhs.uk

Chief Executive's Office
Clocktower
Northern General Hospital
Herries Road
SHEFFIELD
S5 7AU
[redacted]

21 May 2024

Mr S Eccleston
Assistant Coroner
Office of H.M Coroner
The Medico-Legal Centre
Watery Street
Sheffield
S3 7ES

Dear Mr Eccleston

Prevention of Future Deaths Report – Craig John BURFIELD

In response to your Prevention of Future Deaths (PFD) Report dated 26 March 2024 following the very sad death of Craig Burfield, we are very saddened by Craig's death and sincerely sorry for the distress and upset which this has no doubt caused his family.

Given your concerns related to the transition of young people with shunts implanted as a consequence of hydrocephalus, the Regulation 28 Report to Prevent Future Deaths was addressed jointly to Sheffield Teaching Hospitals Foundation Trust (STHFT) and Sheffield Children's Foundation Trust (SCFT). As a consequence we have worked together to agree a joint response as follows.

We acknowledge that the arrangements for transition have not been as robust as they could have been, and we have been working hard to address this. The current transition process is reflected in the SCFT and STHFT Transition Policy and the Cross Trust Transition pathway which have been agreed between the two organisations (enclosed). The Cross Trust Transition pathway details the process followed by both organisations and includes:

- The sharing of local transfer documentation and appropriate healthcare records and, where appropriate, the development of an individual transition plan.
- Arrangements to share information at the point of transfer, in particular, ensuring that patients attend their first appointment after transfer.

To support the transition process there are specialist transition teams at SCFT and STHFT; these teams work closely together to support young people with complex healthcare needs who are transitioning from child to adult healthcare. For patients with complex needs the Transition Teams facilitate a multi-disciplinary team discussion with the receiving specialities to ensure appropriate arrangements are in place. Where appropriate the STH Transition Team would also support with the initial appointment(s) in adult services and where there are likely to be inpatient admissions, arrange visits to the relevant wards.

Children with shunts, who are seen by one of the neurological consultants or by a clinical nurse specialist in the hydrocephalus clinic in SCFT, are transitioned to adult services at around 18 years old, which is in line with other centres nationally.

For young people with shunts SCFT runs a monthly transition clinic where all hydrocephalus patients 14 years old and over are seen by clinical nurse specialists. The more complex hydrocephalus patients or those with other neurosurgical conditions are followed up in a Consultant Neurosurgeon's clinic and they will start to discuss transition with them from around 14 years old as per the SCFT and STHFT Transition Policy. These visits require longer appointment times as they cover a hydrocephalus check and discuss preparation for transition. At the last appointment before transition the patient is provided with contact details for the Neurosurgical secretaries so that they know who to contact if they have any concerns about their symptoms between appointments in the adult service.

When transition is confirmed, SCFT will refer the patient by letter to the Neurosurgical team at STHFT and request an appointment. Some consultants work at both SCFT and STHFT so will keep the patient under their care once they transition. Patients will be booked to have a review with a Consultant Neurosurgeon who will clarify follow-up requirements. When the patient is complex, the transition team will provide support as detailed above. Following their first appointment in the adult clinic, care is transferred. Prior to this, patients are informed to contact SCFT.

There is no clinical requirement for the routine review of shunts, however during appointments both before and after transfer, patients and/or their families are made aware of the signs and symptoms of a blocked shunt and what action they should take. If, following transition, a decision is made that further routine follow-up is not required, the patient will stay active on the neurosurgery pathway. Patients will be provided with contact details, so that the patient and family are aware of who to contact, including the Consultant's secretary, for non-urgent enquiries or the on-call Neurosurgeon for urgent enquiries.

Following the concern raised by Craig's inquest, we will formalise the process with a written pathway so that it is clear to both SCFT and STHFT what process these young people will follow when transitioning to adult services. This will be complete by September 2024.

We recognise that, as life expectancy increases, we will be seeing increasing numbers of patients with Neurodevelopmental disorders transitioning to adult services. Neurodevelopmental disorders have a spectrum of severity and underlying disease processes. Individuals may have difficulty in a wide range of areas, requiring referral to many secondary care specialties including ENT, ophthalmology, orthopaedics, urology, gastroenterology, plastic surgery, spinal injuries, neurology, and neurosurgery. The STH clinician to whom the individual is referred tends to have a focused skillset and interest limited to one aspect of that individual's neurodevelopmental disorder, e.g., shunt, epilepsy, or spasticity, which for many of these individuals is not their active or main problem(s). At present, STH does not have a designated service for adults with neurodevelopmental disorders equivalent to the paediatric neurodisability service. Subject to funding being identified an adult neurodevelopmental disorder service may be developed in the future.

Early in 2023 the South Yorkshire & Bassetlaw Acute Federation Trust Paediatric Innovator Programme was established, which includes a project on standardising developmentally appropriate healthcare for young people with chronic or complex conditions transitioning from paediatric to adult secondary care. This is a provider collaboration between STHFT, SCFT, Barnsley Hospital NHS Foundation Trust, Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust and The Rotherham NHS Foundation Trust. It is one of nine national provider collaborative innovators. The project aims to ensure that there are defined clinical roles, patient involvement and training resources for staff to support young people transitioning from paediatric to adult care across all partner trusts, processes that support healthcare transition in line with NICE guidance including personalised healthcare plans and a standardised way of tracking patient numbers through the system.

Having outlined the actions we are taking in response to your report, I hope that I have been able to convey how seriously we have viewed this matter. We are committed to learning from Craig's death and implementing these actions.

Finally, We hope that our response has addressed the concerns and actions you identified in your Report. Please contact us if you have any queries or points of clarification.

Yours sincerely

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Chief Executive STHFT

Ruth Brown
Chief Executive SCFT

Enclosures
1 – SCFT - The Transition from Children's to Adult Services Policy
2 – Cross Trust Transition Pathway
3 – STHFT - Policy and Guidelines for Transition of a Young Person to Adult Services