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Dear NAME,

I am writing to submit a formal complaint against the Board of Buckinghamshire Healthcare NHS Trust (BHT) in relation to the mismanagement of the National Spinal Injuries Centre (NSIC) at Stoke Mandeville Hospital.

As a patient and service user of the NSIC I have lost confidence in BHT’s management of the NSIC for the following reasons:

**Point 1**

BHT is currently using half of the rooms within the Spinal Outpatient suite for general outpatient services, and has been doing so for many months. It is my understanding that these rooms within the NSIC are dedicated to, funded for and staffed for the exclusive use for clinicians to review and treat spinal outpatients.

In his recent statement in the NSIC Facebook group, Andrew McLaren (recently appointed Chief Medical Officer) responded to many comments made by patients about various issues with the current management of the NSIC. On the subject of “outpatient services” he said *“We would like to sincerely apologise for the disruption that has been caused by the temporary relocation of some of our general outpatients services into the NSIC building. This has been necessary due to the work that is underway to create a new children’s emergency department and obstetrics & gynaecology building at Stoke Mandeville Hospital.”*

However, Mr McLaren failed to give a timeframe for this relocation of general outpatient services. This loss of facility is **severely** impacting the NSIC spinal patient communities’ ability to access spinal outpatient services. The NSIC provides extremely specialist nursing and medical care to a population who are often simply not safe in general hospitals due to a lack of specialist knowledge.

Every newly injured patient who comes into the NSIC is promised a lifetime of support for their spinal health needs. This is also a **requirement** of the services provided by a spinal cord injury centre, as outlined in paragraph 1.2 of NHS England’s Spinal Cord Injury Services’ Service Specification – *“4. Life-long follow-up of people living with spinal cord injury to prevent and manage SCI related complications.”*

With several thousand spinal patients relying on the NSIC’s outpatient services this is a matter that needs rectifying urgently. **Losing access to spinal outpatient staff expertise and facilities is compromising patient’s health.** Given the history of BHT claiming use of spinal beds and wards, only to then have funding removed (please see Point 2 of this letter), you will understand the widespread fear, loss of trust and worry that the use of Spinal Outpatients is causing to the NSIC patient community.

We are asking BHT to remove the general outpatient services from the NSIC Spinal Outpatient suite **immediately**.

**Point 2**

St Joseph ward was an extremely important part of each and every patient’s journey through their rehabilitation at NSIC. St Joseph ward was funded, staffed and dedicated to increasing patient’s re-enablement and independent living skills prior to reintegration to the community. It was designed to run as a pre-discharge ward with specific objectives and goals for patients that often were not achievable on other wards. It also provided safe and specialist maternity care to spinal cord injured pregnant ladies both pre and post delivery, as well as the Cauda Equina service and bowel and bladder training services.

Between 2015 and 2017 BHT took over St Joseph ward for their own use for general patients. **This use of the spinal ward by BHT for non-spinal patients resulted in NHS England withdrawing their funding** for the 16 beds on St Joseph ward in 2017. BHT are responsible for the loss of funding for St Joseph ward.

The devastating loss of this ward demonstrated a complete lack of understanding by BHT to comprehend the impact for all present and future NSIC patients. Furthermore, with the critical lack of spinal beds across the country, it was, and continues to be, a huge loss to the entire national spinally injured community and further demonstrates that BHT are not fit look after our best interests. The specialist care, services and independent environment that were so carefully curated on St Joseph ward are unable to be provided elsewhere in the unit and have largely since been lost.

St Joseph ward is still **very much** needed by NSIC patients, and must be returned to the NSIC for use by NSIC patients.

**Point 3**

The patient forum has been a tick box exercise by BHT which is demonstrated by the fact that it has not met in over a year.

The forum was created in response to pressure from patients who were outraged when NSIC lost the funding for St Joseph ward and outliers occupied beds on spinal wards. While BHT did make some small changes as suggested by the patient forum when it was first formed, the forum has since completely fallen by the wayside. The current membership is not reflective of the NSIC patient community and is not kept up to date or informed of happenings within the NSIC, for example, the take-over of Spinal Outpatients.

The patient forum should be a democratically elected membership which is able to influence the decisions made in the management of the NSIC and that the management of the NSIC is answerable to.

**Point 4**

Many NSIC patients have been told by doctors within the NSIC that their annual outpatient review, associated imaging and standard procedures, such as cystoscopy, are no longer possible through the NSIC and that NSIC policy is now to refer patients to their local hospitals. NSIC have a requirement, as outlined in Point 1 of this letter, to “l*ife-long follow-up of people living with spinal cord injury to* ***prevent and manage SCI related complications****.”*

It is not possible to prevent and manage SCI related complications through the spinal injury centre if life-long follow up is no longer provided through the spinal injury centre.

Referring spinal patients to local services for procedures, when local consultants have never heard of autonomic dysreflexia and do not know the dangers of it or how to monitor for it, let alone how to treat it, is life threatening. This policy cannot be allowed to happen.

Please clarify your policy in regards to both NSIC outpatient follow up and readmission for procedures as there is much confusion and consternation amongst NSIC patients.

**Point 5**

Another requirement of a spinal cord injury centre, as outlined in the Spinal Cord Injury Centre Service Specification is that of effective communication - “1.2.9. **Channels for effective communication** between the SCIC and patients, families, service providers, and local commissioners.”

Currently, there is no communication between the NSIC and their out patients. The NSIC used to produce a SCI News newsletter which updated patients on events, new programmes, goings on within the NSIC, new and retiring staff and it kept us all up to date. This hasn’t been produced in at least 5 years – the last mention of it on the NSIC website is in 2015.

Where/how do our patients or our families go for advice, information or get access to our consultant? NSIC’s Spinal Outpatient’s service is drastically reduced due to BHT’s actions, clinics are running years behind, there is a national shortage of spinal beds, NSIC’s outreach service is exclusive to referral hospitals for patients waiting to be admitted to the NSIC, and the NSIC itself is referring its own patients away to local services.

**Furthermore**

It is my understanding that the NSIC has always brought money into BHT and provided a surplus of funds. The NSIC used to have independent management and structure.

BHT’s objectives are regional and local services and it does not list any objectives for spinal injury.

Under BHT’s management, the unit has gone from 126 beds, to 110 beds with the loss of St Joseph ward, to now only having 102 beds, with a loss of 8 further beds. BHT continues to undermine and dilute the service provided by the NSIC. This cannot be allowed to continue.

The NSIC should be managed independently of BHT and it should have control of its own budget, objectives and independence.

**To Summarise**

It is my opinion, given the evidence, that BHT have proved themselves unable to provide management that is fit for purpose and continue to use NSIC space for their own gain, resulting in loss of funding and reduction of services to their own patients and to the national SCI community.

· **REMOVE NON SPINAL SERVICES FROM SPINAL OUTPATIENTS**

· **GIVE US BACK ST JOSEPHS**

· **GIVE US A SAY**

· **KEEP YOUR PROMISE TO LOOK AFTER US** **FOR LIFE**

· **GIVE US ACCESS TO COMMUNICATIONS, CLINICIANS AND SERVICES**

· **RING FENCE THE NSIC & REMOVE BHT**

The management of the NSIC needs urgent intervention.

We have already lost enough of the NSIC to BHT and are not prepared to lose anymore.

Yours sincerely,

NAME