Supporting Clinical Evidence for Business Case to Develop a Neuromuscular Complex Care Centre

NMCCC

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Executive Summary
This business case has been developed to improve access to specialised services for a rapidly growing and severely disabled patient population with neuromuscular and neuro-metabolic disorders with highly complex medical needs.

This patient group have profound muscle weakness and typically have multiple organ dysfunction including respiratory, cardiac and gastrointestinal systems. Clinical evidence shows that specialist, timely, multidisciplinary care can increase quality of life and double life expectancy. In Denmark average survival is 50 years in London it is 24 years.

Previously this patient group did not survive into adult life. Paediatric care advances have now resulted in increasing survival and transition of significant numbers of patients into adult services. This is a new and growing population of patients with highly complex care requirements.

We have collated significant evidence that currently at UCLH, and across the NHS, patient experience, patient safety and patient outcomes are all poor.

Frequently, this patient group experience fragmented care provided across several hospital Trusts and primary care. The lack of appropriate hospital facilities and untrained staff often leads to poor patient experience, poor quality of care and absence of NICE compliance. There is frequently avoidable delay in treatment for predictable inter-current illnesses, often resulting in prolonged hospital stays and avoidable intensive care admissions.

We recently worked jointly with London specialist commissioners and undertook an audit of over 600 patient emergency hospital admissions in patients with these diseases admitted acutely to 12 different Trusts. We showed that 40% of urgent admissions for this patient group were avoidable. Patient presented urgently with known and predictable disease complications. Typically patients had ~10 days warning symptoms before acute deterioration and emergency admission. These unplanned emergency admissions are estimated to cost NHS London >£10m per year.

By designing a pre-emptive specialist care system the current fragmented care arrangements can be avoided. The pre-emptive elective centre will reduce unplanned emergency admissions, improve patient experience and improve patient safety. Furthermore, the care systems put in place, with the Neuromuscular Complex Care Centre at the hub, will enable patient outcomes similar to international bench marks for survival, so mean survival in London (currently 24y) can match Denmark 50y.

UCLH will be the first trust in the UK to open a dedicated NMCCC and we anticipate other regions will follow this UCLH flagship centre.
• Brief overview for Executive Board
• (full 100 page document with all supporting evidence available)

Aims
• To develop Britain’s first dedicated elective in-patient facility for severely disabled adults with neuromuscular (NMD) and metabolic disease.
• Develop a ‘hub and spoke’ model of care.
• Meet NICE accredited standards of care – currently not met.
• **Reduce NHS costs** – cost of unplanned emergency hospital admissions for London >£10m
• Provide **Elective** pre-emptive short stay admission to **prevent** emergency ITU admission
• Provide closer community links: 24 hour telephone **advice line** for patients and day-time **outreach** to local hospital/ home for assessment and management
• **Improve quality** - patient experience currently poor
• **Improve outcomes** – UK worse life expectancy than Denmark
• To **increase** market share of a **new pool** of patients, who would have previously died in childhood (**similar to cystic fibrosis situation in 1990s**)

Background
• The Queen Square Centre for NMD (CNMD) provides **world class** integrated clinical and translational research for NMD.
• A transition service for NMD between GOSH and CNMD was established in 2009 – **expanding new pool of patients.**
• Although UCLH is one of the largest and most successful Trusts in London it does **not provide a non-invasive ventilation service** (NIV).
• Patients currently being treated with NIV at GOSH have **no** satisfactory transition arrangement.

Evidence supporting the clinical case
• The **Walton report** highlighted poor NMD care across the UK, 50% of adults do not access any specialist NMD service
• In 2011/12 the largest ever audit of unplanned NMD admissions across 4 regions showed that **40% acute admissions were avoidable** (Hanna et al) Audit was presented to the all parliamentary group for NMD and endorsed by Baroness Thomas, Lord Walton and muscular Dystrophy Campaign, covered by BBC
• **The average length of stay for a PEG in patients at NHNN is 8-12 weeks** BEFORE the procedure because:
  • Patients have highly complex needs, **close coordination is essential** across multiple medical specialties: respiratory, cardiology, gastroenterology, anaesthetics
  • NIV currently managed by other hospital Trusts- **substantially delays anaesthetic and increases risk**
  • Cardiomyopathy management by other hospital Trusts- **substantially delays anaesthetic and increases risk**.
  • UCLH/NHNN lacks facilities and experienced staff to optimise pre and post-anaesthetic NIV management

• Currently ITU/HDU bed required post-anaesthetic for NMD patients needing NIV- **ITU/HDU capacity issues** result in late cancellations
• **Cost to UCLH-2 examples:**
  • £29,800 for a 4 month admission (total cost to NHS £33,600)
  • £10,800 for an 8 week admission (total cost to NHS £11,934)

• An audit of transition of NMD patients at CNMD (2012) **highlighted patient and carer concerns about the patient journey, patient experience, patient safety**. Identified **gaps** in adult services for **young adults with NMD** e.g. lack of facilities, lack of appropriately trained staff, concerns that untrained doctors and nurses would not recognise NMD complications or know how to manage them

**Solution**
• Establish UK’s first highly specialised **neurology centre** providing **pre-emptive, co-ordinated, multi-disciplinary care**. The centre will be **adapted, equipped and staffed** to meet patient needs
• Capital costs (including equipment) have been provisionally **approved by UCLH Trustees**
• 6 dedicated in-patient beds located on ground floor of Chandler wing opposite Molly Lane Fox
• Number of beds sufficient to cover anticipated growth in next 5 years and test untapped new market
• Basil Samuel outpatients planned relocation—opportunity for expansion if required in future (area will be designated for inpatients)
• Majority of patients are male, en-suite cubicle and elective planning will ensure compliance with separate sex rules
• ‘Productive ward philosophy’—‘release time to care’, lean methodology with regular monitoring and review to increase efficiency, patient experience, quality of care and staff experience
• Nurses to rotate with general neurology wards and intensive care—widen experience across NHNN
• Close working support other specialities: Respiratory medicine, Anaesthetics, Cardiology, Gastroenterology, SALT, physiotherapy, dietetics, respiratory physiology, psychology
• Comply with NICE standards of care, develop streamlined care pathways—improve patient experience, reduce length of stay, improve outcomes, reduce unplanned admissions—reduce NHS cost
• 24 hour telephone contact to unit will be first point of access for patients. Advice to prevent further deterioration or to seek urgent care locally
• Outreach will be provided by a CNS—follow up advice calls, link with community, palliative care teams and local hospitals to ensure best outcomes.

Benefits
• Attract new in-patient and out-patient income to Trust by increasing market share of an untapped population
• Improve efficiency and reduce waste i.e. reduce unnecessarily prolonged admissions for procedures, better co-ordination of care, lean methodology
• Support medical specialties e.g. gastroenterology by providing co-ordinated anaesthetic, neurological, respiratory and cardiac care
• Develop expertise in delivering a high quality NIV service for complex patients with transferable skills for other departments across UCLH Foundation Trust
• Reduce unplanned admissions, especially lengthy ITU admissions and reduce cost to the wider NHS
• Meet NICE standards of care for DMD and MND, currently not met, and international standards of care for SMA and CMD, currently not met.
• Enable NHNN to meet standards of care in SCG service specification currently not met
• Improve patient outcomes c.f. international benchmarks such as Denmark
• Improve patient experience and safety
• Profitable business case exceeds Trust margin
SM is a 19 year old man with DMD. His parents had no concerns until he was 4 years old when a school teacher noticed that he could not run. By the age of 10 years he had lost the ability to walk independently. With advancing age, his condition has deteriorated to the extent that he is now completely paralysed he can only move his face and one thumb.

At the age of 15 he was diagnosed with cardiomyopathy and takes regular medication. His cardiac care is managed at the Hammersmith hospital where he is seen once a year.

At the age of 16 he developed respiratory failure and was started on non-invasive ventilation by the Royal Brompton hospital. 18 months ago he developed a chest infection but could not contact his respiratory consultant for advice. His condition worsened and he was admitted to his local hospital where he spent 6 weeks on intensive care. His experience in hospital was poor, the staff did not know about his condition and lacked confidence. He lost a great deal of weight and a gastrostomy was considered. A speech and language therapy assessment raised concerns regarding the safety of his swallow.

He now needs to use his NIV for 12 hours each day. He requires a machine to help him cough. His parents are his carers and never leave his side. They have to turn him 6 times at night and they feed and dress him and provide all of his personal care. He cannot even scratch himself when he has an itch.

He attends 7 outpatient clinics a year at different hospitals and at least one elective admission each year to assess his NIV. Hospital transport is always a problem and travelling makes him very tired. He never sees a physiotherapist or psychologist. He doesn’t like going into hospital because the hoist doesn’t work well and he feels unsafe as he sleeps in a cubicle at the bottom of a busy ward.

He describes his quality of life as very good, his cousin visits at weekends and they enjoy playing on a play station together. He likes going to restaurants to eat curry and Mac Donald’s. When asked about resuscitation he says ‘he wants to live as long as possible’.