Chronic Fatigue Syndrome

You said

Clinicians

- Is there the skill and expertise in the community (the NUH CFS team has over 10 years' experience with this patient group) and will there continue to be the same standard of care?
- Concern over proposed discontinuation of group therapy
- Will the future procurement be outcome based?
- NICE guidance is out of date

Patients

- Current service in the hospital is not easily accessible
- CBT really useful
- Group therapy is beneficial for managing the condition
- Eight week intensive course very helpful
- Support the idea of the CFS service moving into the community

Our response

While we recognise that there is a lot of expertise in the NUH CFS team, and that patients and clinicians see benefit in group sessions, at the same time patients tell us that it is difficult to access services at the hospital and they'd welcome services in the community.

We remain committed to ensuring that our local population have access to the specialist elements of the CFS service as described in the NICE guidance. We recognise that this guidance was issued in 2007, and when it is updated, we will review our commissioning to ensure that we continue to meet any new requirements.

We plan to integrate the service into the community. This service will:

- Be delivered by a multi-disciplinary team with appropriate CFS specialists that can triage all referrals and manage patient's physical, psychological and social needs
- Act as a single point of access for patients with CFS providing a simpler patient journey
- Provide a holistic assessment and management approach for patients with chronic pain or CFS as early as possible in the pathway
- Support patients living with chronic pain or CFS and their nominated carers to:
    - manage their own condition and make decisions about self-care
    - allow them to live as independently as possible continue care and support (where appropriate) learnt through the service post discharge
- Provide appropriate access points following discharge to support in the management of flare ups and avoid re-entry into the service where possible
- This service will provide evidence based interventions only, as identified by NICE, which means that group therapy that is currently provided will not continue.

Motor Neurone Disease

You said

Charity feedback

There is concern that community teams do not have the required level of capacity, resource and expertise of the highly complex needs of people living with MND to deliver these services effectively.

Patients

Concerned if visits are from the community team and not specialist trained MND nurses etc.
A lot of concern about losing the specialist care

Our response

We can reassure patients and clinicians, the the CCGs will ensure the re-commissioning of these services to maintain the current principles of crisis management, rehabilitation, self-management.

This service change is focused purely on home visiting co-ordination and not wider regarding current MND specialist services, so it would still be the case that if specialist support is needed for patient care then this would be achieved by linking with current specialised MND services. Examples of this would include, need for complex advice and support with referral / input from lead consultant at NUH, a referral to home ventilator nurse and discussion with the patients GP regarding prescribing.

The functions of the home visiting component are already currently available within the community. Moving the service out of the acute setting allows for improved integration of care and as a result a greater emphasis on patient outcomes.

It is expected that the patient experience will improve through integration of services.

Earlier in a patients disease journey the delivery of NICE quality standards would be supported through attendance and engagement with specialised secondary care MND services which are unaffected by the locally priced reviews.

Pain management and back pain

You said

Clinicians

- Current team is very experienced
- Patients are vulnerable with physical, psychological and social difficulties
- Chronic and lasting pain is complex and context sensitive
- Evidence based management that differs from other conditions and requires specialist service

Patients

- Substantial concerns on not having access to injections
- Services allow individuals to maintain activities of daily living
- All areas of therapy need to be together
- How will equipment be accessible in community

Our response

Firstly, the service is commissioned to July 2017 and so is currently continuing to see patients. Moreover, we recognise the NPBT delivers its service in community locations but this is not the case for other outpatient pain services which are hospital based.

The proposed service model recognises the need for a multidisciplinary team of therapists with the relevant expertise to support people living with long term chronic pain and this is included within the service specification. The CCGs wish to consolidate existing service provision within an integrated community pain service to ensure that all pain management services are provided as close as home as possible.

The new specification covers all elements of the service provided to people living with chronic pain, including the available evidence for when injections are effective in managing pain to ensure that people receive the most appropriate treatment for their needs. The work has also included setting out a standardised approach for GPs to follow to ensure that all patients receive the same level of care, irrespective of the GP practice they attend, and indeed the individual GP they see for an appointment.

This is the standardised approach to the management of choric pain that CCGs wish to commission, not a standardisation across different conditions. The review of the clinical and cost effectiveness interventions is referenced in the service specification.

CCGs are working with practices on an ongoing basis to ensure that choice for an appointment or test is offered when it is appropriate to do so.

Any new service providers will be expected to work closely with the current service provider to agree a transition plan to ensure that patients continue to receive the care they need. As such we would expect this to be clearly communicated with your son as soon as any new provider has been confirmed.

Complex rehab (geriatric day care)

You said

Clinicians

- Medical and rehab needs of complex patients has not been considered
- There is a group of patients requiring regular, multi-disp assessment and treatment
- It is not possible to safely manage heavy equipment in the community

Patients

- How will community services have the specialist equipment
- Spec doesn't cover needs of Parkinson's patients
- Group exercise very beneficial
- Peer and social support important
- Compromises specialists ability to treat patients as drugs not only effective therapy

Our response

- This service will be integrated into existing community services
- Commissioners will ensure that future services are skilled appropriately.
- CCGs are not planning to move any other activity, other than the complex rehab service
- CGs will ensure the re-commissioning of these services to maintain the current principles of crisis management, rehabilitation and self-management through a multidisciplinary approach. Care will be closer to home for patients – provided in either a community location with specialised equipment or in the home environment.
- Referral criteria will remain the same, along with a focus on complex falls and complex neurological conditions including Parkinson's Disease.
- Commissioners are currently running focus groups with Parkinson's patients and carers to ensure that the Parkinson's service developed in the community fits their needs - the specification will have a separate
- The delivery model will exclude stroke patients where those stroke patients will be cared for by the specialist stroke community service.
- Rehabilitation following a multi-disciplinary team approach with physiotherapy, occupational therapy and social care would be provided by a community service. Medical review of complex patients within a multi-disciplinary team environment would also include a community geriatrician service and where complex investigations are needed, these would be requested through secondary care (for example, tilt table testing and imaging).

Neuro rehab/ TBI/ Neuro reablement

You said

Clinicians

- Specification doesn't take into consideration reablement and traumatic brain injuries
- Flexibility in length and intensity in treatment
- Working from one base is beneficial to facilitate inter-disciplinary working, including access to equipment

Patients

- Recognise individual needs and responsiveness to care - 12-14 months is not sufficient for every patient
- Traumatic brain injury versus long term condition
- How will patients access specialist skills and equipment?
- The TBI service helps gives people their life back, how will you ensure continuity of care if the service moves into the community?

Our response

- To keep in NUH – commission neuro assessment, traumatic brain injury and neuro-reablement as a single service
- We will update our Quality Impact Assessments and Equality Impact Assessments taking into consideration the new specifications as an integrated service
- We will carry out a short term review of patients accessing services and a longer term review of the entire service

Renal home visiting

Clinicians

- Complex renal patients requiring specialist skills
- Provides specialised system management for patients who are not suitable or do not wish to go on dialysis
- End of life is only a small part of service. Once reach this stage are handed over to the community teams
- If decommissioned NUH wouldn't be able to offer ad hoc telephone advice

Patients

- What about the the loss of experienced staff and their accumulated knowledge over the years and loss of clinical excellence

Our response

- This service will now stay with NUH and be commissioned as a home visiting service alongside home dialysis

Integrated dietetics

You said

Clinicians

- Big risk on fragmentation
- Will inpatient be de-stabilised due to shortage of clinical skills – erosion of skilled workforce in system
- For CKD close link between consultant and dietetics will need to be maintained
- Clinical risk due to communication required with different dietitians across the system

Patients

- You want assurance that support will continue for babies/children with PKU, including during periods of illness
- Must be delivered by clinicians with specialist knowledge including of renal patients

Our response

- This service specification is currently on hold.