

Whittington Health, LUTS update: September 2021

This paper provides an update to the North Central London Joint Health Overview and Scrutiny Committee on the pathways in place for secondary care clinicians to refer adults and children for specialist treatment of lower urinary tract conditions. The specialist service at Whittington Health (WH) is commonly referred to as The Lower Urinary Tract Service or LUTS and has operated from the Whittington Hospital site since December 2020 (previously based at Hornsey Central Health Centre). The WH service is commissioned by NHS North Central London Clinical Commissioning Group (NCL CCG) for the treatment of chronic urinary tract infections in adults in accordance with the provisions of the NHS Standard Contract.

The service is now led by Miss Rajvinder Khasriya, a urogynaecologist, who is a joint appointment with UCLH and supported by a second substantive consultant. The service is further supported by 2 Clinical Fellows and a laboratory technician. Due to the demands of the service a third consultant is also being recruited.

Update on the WH LUTS Clinic for Adults

In June 2019 it was agreed by Haringey and Islington CCGs that GPs would be consulted to determine if commissioners required any further assurances on the LUTS treatment protocol implemented by WH in June 2019.

On 24 October 2019 GPs, senior medicines management colleagues and CCG officers met to agree the commissioners' position on the referral pathway, shared care, the LUTS protocol and future monitoring. Minutes of the joint Haringey and Islington CCG Quality and Performance Committee on 19 December 2019 confirm that the Committee was satisfied with the decisions made by clinicians on 24 October 2019.

WH and representatives of the LUTS patient group were informed of the decisions made by the CCGs on 15 and 16 January 2020 respectively. An outline of the key decisions agreed on 24th October 2019 and a September 2021 update is provided below:

1. Referral pathway

24th October 2019 - Following a detailed discussion led by clinicians, it was agreed that due to the highly specialised nature of this tertiary service the current access criteria (i.e. referral via secondary care clinician) should remain in place.

9th September 2021 - There has been no change to the referral pathway since January 2020.

2. Shared care protocol

24th October 2019 - CCG clinicians highlighted that for a shared care protocol to be in place, individual GPs would need to agree to manage the patient in accordance the LUTS protocol which included the prescribing regimen. Given CCGs cannot

mandate GPs to accept shared care protocols and GPs within NCL were unlikely to agree to deviate from NICE guidance and the local prescribing formulary, it was agreed that a move to shared care could not be supported at this time.

9th September 2021 update - This remains an area of concern for WH. There is no shared care protocol in place to allow the discharge of patients from the service into primary care. Raj Khasriya, Consultant Urogynaecologist is working with Sarah Humphreys, Medical Director to consider options and an acceptable solution.

3. LUTs prescribing protocol

24th October 2019 - It was agreed that queries relating to prescribing would be put to members of the WH Drugs and Therapeutic Committee by the CCG Heads of Medicines Management for consideration when the protocol was formally reviewed in Spring 2020.

9th September 2021 update – The formal service review did not take place in Spring 2020 due to the Covid-19 pandemic. WH Pharmacy manages the dispensing of prescriptions for the LUTS service. There are no changes in the prescribing protocols.

4. Monitoring of the contract during the remainder of 2019/20 and 2020/21

24th October 2019 - In relation to the level of support within the service to support psychosexual needs, the group recommended that the resource allocated was discussed with the Trust and revisited formally as part of the annual review of the contract in Spring 2020.

9th September 2021 update- As mentioned earlier, the annual review of the contract did not take place in Spring 2020 due to the Covid-19 pandemic. As the LUTS is a specialised service, the Trust would welcome a review to assess the rising number of referrals; the difficulties arising from the lack of a shared care plan with GPs to enable safe discharge; and the complexity of cases.

5. Recent Significant enquiries:

There have been three enquiries relating to referral pathways for children to access the LUTS service:

- 1x pre-claim for potential judicial review – legal challenge regarding lawfulness of paediatric oversight. Response sent by Trust solicitor 24/06/2021 – separate responses sent by GOSH & Oxfordshire CCG as also cited. Background advice received from NHSE/I Medical Director
- 2x requests to the service directly to discuss LUTS protocol with a Welsh paediatrician – one from the paediatrician, one from the child's mother
- 1x referral request to Chief Executive Officer via MP Priti Patel 22.06.2021 (Essex) – request for child to access LUTS service. Response based on Trust solicitor's response above

6. Recent engagement with the Patient group – As above, under judicial review response

- 7. Service changes due to Covid** – The service has been impacted by Covid, some virtual clinics continued but many patients required face to face appointments which have had to be delayed. This has had a further impact on backlogs.

Update on pathways for Children and Young People with chronic urinary tract infections

Tertiary pathways for NCL children with chronic urinary tract infections are provided by Great Ormond Street Hospital (GOSH) although they do not offer 'like-for-like' clinic protocols as the adult WH LUTS Clinic.

Historically, a small number of children were treated at the WH LUTS Clinic, but since 2015, no new paediatric cases have been accepted and no children have received care at the WH LUTS Clinic since 2017.

In 2015 WH invited a review of the service by the Royal College of Physicians which was published on 19 October 2016. The report recommended that treatment of children at the LUTS Clinic should be undertaken only with supervision from a consultant paediatrician. The reason for this being there is little research evidence of the benefits of long term, low dose antibiotics for chronic urinary tract infections in children and as such there would be concerns about committing children to the adult treatment protocols without an individual assessment and the input of a multi-disciplinary team to give a holistic treatment plan which should include local services.

WH was unable to source supervision from within the cohort of paediatricians employed by the Trust, as they did not have the experience or expertise to supervise this specialist service. After the retirement of Professor Malone-Lee in 2017, responsibility for care of children with chronic urinary tract infections was transferred to tertiary/specialist children's hospitals such as Great Ormond Street Hospital.

The agreed 'health system' way forward was for children and young people with chronic urinary tract infections to be cared for by their local paediatric nephrologist and their paediatric MDT.

Plans in Q3/Q4 2021/22

NCL CCG will support WH with a LUTS service review prior to establishment of the NCL Integrated Care System in April 2022.

Questions raised by the JHOSC Chair and Responses

1. Has the LUTS patient group been made aware of the latest update?

The LUTS patient group have not been made aware of the 'LUTS September 21 update' as this report was written specifically in preparation for the JHOSC agenda item very recently. WH have confirmed that as there has been no service review, there nothing yet to update or involve the patient group with in regards to service provision. There is currently no future date in the diary for the LUTS Patient Group to meet.

2. This implies stress* in the system. Is there a plan to address this whilst waiting for the review?

9th September 2021 update - As mentioned earlier, the annual review of the contract did not take place in Spring 2020 due to the Covid-19 pandemic. As the LUTS is a specialised service, the Trust would welcome a review to assess the rising number of referrals*; the difficulties arising from the lack of a shared care plan with GPs to enable safe discharge; and the complexity of cases.

The Trust and CCG acknowledge the reported pressures on the LUTS service and the CCG will shortly set up a meeting with WH representatives to review the risks and mitigations and discuss planning and timelines for the proposed service review prior to April 22.

3. I note the pre judicial review within the children services, when will this be heard?

On 24/06/2021, a response was drafted by Whittington Health's solicitors, Bevans, stating that: "In summary, Whittington Health does not have a legal or contractual duty to accept a referral from a child to the Adult Chronic Urinary Tract Infection Clinic in respect of the Claimant." Therefore the action was denied by WH. Since the Trust's response was sent WH have not received any further correspondence from the Claimant's solicitors.

4. Are children being referred to Great Ormond Street Hospital (GOSH) as part of a children's LUT's service or is it dependent on the child's Paediatrician?

The pathway for NCL children referral to GOSH is: i) GP to refer to NCL paediatrician in local acute Trust, ii) paediatrician in local Trust is the gatekeeper to determine whether onward referral to local tertiary paediatric nephrologist (GOSH) and paediatric MDT is recommended course of action.