

**Freedom of Information Request**

**Ref: 23-970**

24 January 2024

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting

**What is the address of your base refill clinic, with postcode?**

Bristol Royal Hospital for Children, Upper Maudlin Street, Bristol BS2 8BJ

**1. How many adults with pumps for spasticity/dystonia do you manage with intrathecal baclofen?**

This service is provided by North Bristol NHS Trust. Please contact [foi@nbt.nhs.uk](mailto:foi@nbt.nhs.uk) for further information.

**2. How many adults with pumps for pain do you manage with intrathecal opioids?**

This service is provided by North Bristol NHS Trust. Please contact [foi@nbt.nhs.uk](mailto:foi@nbt.nhs.uk) for further information.

**3. How many children under the age of 18 with pumps for spasticity/dystonia do you manage with intrathecal baclofen?**

Approximately 35

**4. How many children under the age of 18 with pumps for pain do you manage with intrathecal opioids?**

Approximately 16

**5. Approximately how many pump refills does your service do each month at your usual locations?**

Approximately 12 to 16 per month

**6. Do you accept people attending on a stretcher for refills?**

Yes

**7. How often do you refill pumps away from your base hospital clinic? Eg Once/month, once/year, once in 5 years**

As often as required.

**8. What is the furthest you have travelled from your clinics to refill a pump, in miles or time, in the past 3 years?**

Approximately 23 miles

**9. For the first time, a patient is unable to attend the clinic by wheelchair or stretcher for a planned refill, because of acute illness or transport failure. They are expected to recover and be fit to attend refill clinics in the future. They are 90 minutes drive from your usual refill service base and there is no more local service which could refill the pump before it runs out. Would you plan:**

**a) no refill and when pump runs dry advise local doctors to manage withdrawal symptoms with medication by another route.**

Arrange hospital transport where possible, if not clinically possible then option B.

**b) staff from base clinic travels to refill pump at patient's home or local hospital, before it runs dry.**

**Who would travel? Doctor who runs the service? doctor in training who is rotating through the service? Nurse who refills pumps in clinic?**

One doctor and one advanced nurse practitioner

**Do you arrange second person to travel to chaperone, check procedure or open vials to maintain sterility? No/Yes**

Yes

**Then who? Or a video call to check procedure/programming?**

One doctor and one advanced nurse practitioner would travel to patient's home.

**When refilling away from usual clinic, would you ask pharmacy to prepare a sterile syringe with the total drug to be injected into the pump, or would you aspirate from separate vials at their home, as is usually done in clinics?**

The pharmacy prepare and the team would take along to the patient.

**c) patient transferred to your hospital for in-patient management and refill**

Arrange hospital transport where possible, if not clinically possible then option B.

**d) Other, please explain**

Arrange hospital transport where possible, if not clinically possible then option B.

**10. If you have refilled it once while they are acutely unwell, but subsequently the patient is unable to attend the out-patient clinic by wheelchair or stretcher for any future refills, and resides 90 minutes drive from your usual refill service base, and there is no more local service which does home refills to take over long term management,**

**would you plan:**

**a) no visits for further refills or dose reduction**

**b) no further refills but home visits to reduce ITB dose in stages before pump runs dry.**

**b) regular home visits to refill pump until end of battery life, but pump not replaced.**

**c) regular home visits to refill pump indefinitely and pump replacement at end of battery life.**

**e) patient travels by stretcher ambulance, admitted overnight for regular refills**

**f ) Other, please explain**

Option E, but we would likely discuss withdrawal of pump and conversion to oral.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer  
University Hospitals Bristol and Weston NHS Foundation Trust  
Trust Headquarters  
Marlborough Street  
Bristol  
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

#### Publication

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To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

**Freedom of Information Team  
University Hospitals Bristol and Weston NHS Foundation Trust**