

Freedom of Information Act 2000 – Request Reference FoI/24/001
Intrathecal Drug Delivery Pumps

I am writing to all hospitals in UK and Ireland which provide intrathecal therapy services to enquire about their practice or policy for managing patients with pumps, when they cannot attend the clinic for a refill.

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

University Hospital of Wales, Heath Park, Cardiff, CF14 4XW.

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

67 adults.

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

68 adults.

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

After considering your request, the Cardiff and Vale University Health Board (the UHB) believes that section 40 of the Freedom of Information Act 2000 applies. Due to the low numbers of individuals involved, the UHB believes that, when considered with other information already available within the public domain, disclosure would result in the risk of individuals becoming identifiable.

The data requested is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018. Its disclosure would be contrary to the data protection principles and constitute unfair and unlawful processing with regard to Articles 5, 6, and 9 of the GDPR. We are therefore withholding this detail under section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

Nevertheless, we can inform you that refills for children with pumps for spasticity are not conducted by the UHB, rather they are done in Bristol.

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

The UHB does not hold this information.

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

An estimated 40 refills per month for the adult service.

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.

One outreach clinic weekly.

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

40 miles to attend the outreach clinic.

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.
- 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?

Do you arrange second person to travel to chaperone, check procedure or open vials to maintain sterility? No/Yes, then who? Or a video call to check procedure/programming?

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?

- c) patient transferred to your hospital for in-patient management and refill
- d) Other, please explain

The UHB does not hold this information. The Freedom of Information Act 2000 creates a right of access to recorded information. A public authority does not have to create new information or provide opinions or judgements that are not already held in recorded form.

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

The UHB does not hold this information. The Freedom of Information Act 2000 creates a right of access to recorded information. A public authority does not have to create new information or provide opinions or judgements that are not already held in recorded form.