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| Reference: | FOI.3798.20 |
| Subject: | Individual Patient Funding Request (IPFR) applications |
| Date of Request: | 14 August 2020 |

Requested:

1. How many IPFR applications have you received from 2017 to date, from adult lupus patients for lupus related referrals, to either lupus experts or Centres of Excellence in England?
 - 2017 is relevant in that the NICE BSR Guidelines for the Management of Adults with SLE were introduced this year)
2. How many of those IPFR to England were agreed?
3. How many IPFR applications have you received from 2017 to date, from adult lupus patients for lupus related referrals to Consultants inside Wales?
4. How many of those IPFR were agreed?
5. What were the reasons given to reject the IPFR application for lupus patients?
6. Addressing to the current IPFR system, could you please just clarify for me, are their regional variations to the policy regulations contained in the “NHS Wales Policy Making Decisions On Individual Patient Funding Requests (IPFR) dated June 2017”?
7. Again, with the current IPFR system, please confirm whether this must be signed by a Consultant, or whether a GP can sign it, as this is again an area of great confusion with my members and their GPs. Some are told that a GP could sign it and others that it needs to be a Consultant. Please clarify this.
- 8a. Please also confirm that, you must exhaust all local options for Rheumatologists before an IPFR to see a Rheumatologist out of area is considered. So, under Hywel Dda UHB that would mean seeing 5 different Rheumatologists, approx., before you would be allowed to be considered for an IPFR to go out of your health board catchment?
- 8b. Is this really how the system works?
- 8c. I cannot find reference to this in your (WHSSC) policy document?
9. We have been told that once you have exhausted local options, you would be considered for an IPFR – but that would be directed to the neighbouring health board only. You are not even then allowed to be referred outside of Wales – even though all Centres of Excellence are outside of Wales? Please confirm whether this is true.
10. Can you please explain how this sits with what I have been told about our system, i.e. that in Wales where second opinions are granted they should be from someone of the relevant expertise and that second opinions are rarely turned down?
11. When an IPFR is considered for a lupus patient, is there a lupus expert or Rheumatologist on the panel?

12. If an application is decided on factually inaccurate information, should they be reconsidered automatically? Or does the applicant have to appeal?

Response:

1. Hywel Dda University Health Board (UHB) confirms it has not received any Individual Patient Funding Request (IPFR) applications for lupus related referrals. However, the UHB has received seven (7) Prior Approval Applications for referral to England for the period requested. To clarify, out of area referrals are considered in line with the guiding principles and criteria of the NHS Wales Prior Approval Policy and not the IPFR Policy, which are two different policies that link together.
2. The UHB is unable to provide you with the exact number of agreed Prior Approval requests for lupus related referrals to England due to the low numbers of cases (5 and under), as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the Data Protection Act 2018/ General Data Protection Regulations 2016 (GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles 6 and 9 of the GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.

In reaching this decision, the Data Protection Act 2018/General Data Protection Regulations 2016 defines personal data as data which relates to a living individual who can be identified solely from that data or from that data and other information which is in the possession of the data controller.

3. The UHB confirms that less than five (5) Prior Approval Applications were received to out of area providers, but were within Wales for the period requested.
4. The UHB confirms that all of the Prior Approval Applications were approved.
5. The UHB confirms that an appropriate NHS secondary care consultant, or a GP with the support of an appropriate NHS secondary care consultant, needs to demonstrate that all local service provision has been exhausted in order for an external referral to be considered for an 'expert' opinion.
6. The UHB confirms that there are no regional variations to the policy regulations contained in the NHS Wales Policy Making Decisions On Individual Patient Funding Requests (IPFR).
7. The UHB confirms that the IPFR application forms are completed by the treating clinician on the patient's behalf, ensuring adequate clinical information is provided to aid the decision making process. Applications for specialised and tertiary services should be completed by the patient's secondary care clinician, unless extenuating circumstances dictate otherwise. All applications should demonstrate support from the relevant clinical lead.
- 8a. The UHB confirms that out of area referrals are not considered via the IPFR process, they are considered via the guiding principles and criteria of the NHS Wales Prior Approval Policy.

Section 5.1 states that "if a second opinion is required for routine treatment out of area, the requesting clinician must demonstrate that the patient has exhausted all local options where

possible. The patient should first receive a second opinion from a consultant colleague within the same Health Board and then from a Health Board or English NHS Trust with whom a contractual agreement is held.

Section 5.2: The NHS secondary care consultant or other care provider, for example a GP or dentist, with the support of an NHS secondary care consultant where available, needs to demonstrate that all local and locally commissioned service provision has been exhausted in order for an external referral to be considered for an 'expert' opinion. In addition, for reasons due to lack of local expertise, the clinician must demonstrate that the referral being made is to an 'expert' within that specific clinical speciality.

A copy of the NHS Wales Prior Approval Policy can be found by accessing the following link:
<http://www.wales.nhs.uk/sitesplus/documents/862/702-AWPriorApprovalPolicy..pdf>

- 8b. The UHB confirms yes, a patient would normally need to see two (2) Rheumatologists, the one whose care a patient is currently under and a consultant colleague within the same Health Board, where possible. If it was demonstrated that there was a lack of local and locally commissioned expertise, the treating consultant could refer out of area to an expert within that specific clinical speciality.
- 8c. The UHB confirms the above details are referenced within the NHS Wales Prior Approval Policy, provided at question 8a.
9. The UHB confirms that out of area referrals are considered under the NHS Wales Prior Approval Policy and not through the IPFR process. As provided at question 1, the IPFR and NHS Wales Prior Approval policies are two separate processes but are linked.

If a service is not available locally or within existing commissioned services then consideration may be given to an external referral in line with Section 5.2 of the NHS Wales Prior Approval Policy. I.e. where the local NHS secondary care consultant is able to demonstrate that all local and locally commissioned service provision has been exhausted and the referral is being made to an 'expert' within that specific clinical speciality.

10. The UHB confirms that when requests for second opinions are submitted in line with the guiding principles and criteria of the NHS Wales Prior Approval Policy, they are rarely declined.
11. The UHB confirms that an IPFR is not required for lupus patients to be referred out of area. There is no lupus expert or Rheumatologist on the Prior Approval Panel and would not be necessary as the referral should be made by the patient's treating Rheumatology Consultant on the basis that all local and locally commissioned service provision has been exhausted.
12. The UHB confirms that all Prior Approval requests are managed by the Referral Management Team and are considered on individual merit using the guiding principles and criteria outlined in the NHS Wales Prior Approval Policy. Decisions are based on the clinical circumstances of the individual patient. Therefore, it is important to ensure adequate clinical information is provided to aid the decision making process. If the application does not meet the guiding principles outlined in the policy, the prior approval request will be declined. If new or additional data becomes available, the request will automatically be scheduled for reconsideration.