

Advocacy Toolkit:

Individual Patient Funding Requests (IPFR) – Wales

What are they?

Individual Patient Funding Requests (IPFRs) are the NHS Wales procedure for an individual to gain access to funding for services or treatments not routinely provided by the NHS.

There are three instances whereby a treatment may not be routinely available:

1. The treatment is new or still being developed and has not yet been appraised by NHS bodies.
2. The treatment is provided by the Health Board, but the patient is not eligible according to the treatment policy.
3. The treatment for a rare or specialist condition is provided by the Welsh Health Specialised Services Committee (WHSSC), but the patient is not eligible according to the treatment policy.

The criteria for an IPFR

In the first instance, whereby the clinician is requesting a new or developing treatment that has not yet been appraised for NHS use, there must be significant evidence of the following for an IPFR to be passed:

- **That the patient will likely gain significant clinical benefit from the treatment.**

This would involve demonstrating that the treatment would significantly benefit the patient compared to alternatives already available (even if this is supportive care).

- **There is reasonable value for money in treating the particular individual**

Value for money is described as the cost of the treatment per quality adjusted life year (QALY), which is the number of years of life at full health gained by the treatment. QALYs, therefore, consider how treatments will extend life and what the quality of life for the patient will be.

If the patient is not eligible for the treatment under current guidelines, e.g. the treatment has been approved for use but not for the patient's condition, significant evidence for the following criteria must be given:

- **The patient's clinical circumstances are significantly different to the general population of patients with similar condition.**

For a patient to be significantly different, the presentation of their condition will likely not have been considered when deciding on the policy for the general population of patients.

- **The patient will benefit significantly more than normally expected from the treatment.**

This would involve demonstrating that the treatment would significantly benefit the individual patient more so than it would the general population of patients.

- **There is reasonable value for money in treating the particular individual.**

Value for money is described as the cost of the treatment per quality adjusted life year (QALY).



Who can apply?

Patients cannot apply for an IPFR themselves; their clinician (doctor or other healthcare professional) must apply on their behalf. This is to ensure this is sufficient clinical evidence for the IPFR. The consultant must sign the application indicating the patient is fully informed and agrees to the submission of a request.

The Process (Standard application)

All IPFRs are processed on an individual case-by-case basis.

Application sent to IPFR co-ordinator of Health Board

- The clinician submits the IPFR with relevant support from a patient's clinical team and necessary clinical evidence
- The IPFR co-ordinator will return any IPFR with insufficient information and clinicians are given 20 working days to re-submit.

IPFR Screening

- IPFR senior officer will screen the application
- An application will be removed from the process if the treatment is already available via other routes, there is a suitable alternative, or the request represents a service development or policy issue

Consideration by the IPFR panel

- The IPFR panel meet at least once a month and consists of directors of public health, medicine, nursing, pharmacy and clinical science and two lay representatives.
- The IPFR will be anonymised, but may request clinician attendance
- A decision on the IPFR will be given based on the criteria set out in the IPFR policy

Application accepted

- The referring clinician will receive a letter within five working days about the outcome of IPFR
- Patients will receive a letter stating that a decision has been made and the clinician should be in contact to discuss. If this does not happen within five days, contact the clinician.

Application Rejected

- Letters will be sent the same as above, but if declined the clinician can request detailed information on how the decision was made.
- Patients or clinicians can request a review of the decision within 25 working days of receiving the decision letter. This can only be done if they believe:
 - 1) The health board have failed to act fairly and in accordance with the IPFR policy
 - 2) The health board decision is irrational in light of the evidence submitted.
 - 3) The health board has not exercised its powers correctly



The Process (Clinically urgent cases)

If a case is clinically urgent the application will be screened outside of the normal process. The chair or vice chair of the IPFR panel can make an urgent decision on a treatment up to a certain financial limit. The decision will be considered within 24-48 hours.

How likely are IPFR's to be accepted?

Between 2012 and 2016 around half of IPFRs were accepted by Health Boards across Wales. Data from the Cardiff and Vale Health board demonstrated that between November 2011 and July 2012 cancer medicines accounted for 75% of IPFRs and of these requests, a third were accepted.

The IPFR policy has since been updated, in 2017, to make the criteria more accessible and clearer to applicants and Health Boards.

What options do you have if an IPFR is rejected?

Compassionate use

This is the free provision of treatments by a pharmaceutical company. A patient can usually only access these programmes if they have a chronic, life-threatening or seriously debilitating disease and have exhausted all other treatment options approved for use. A specific type is the early access programme, which gives patients compassionate access to treatments that are undergoing clinical trials but have not yet been approved.

Self-funding

You can choose to self-fund a treatment that is not available on the NHS. However, you need to assess whether this option is right for you as you may need the treatment over a prolonged period of time and cancer treatments can be very expensive. For example, a previous report suggests the average annual cost of cancer treatment for one NHS patient is £30,000.

To read the full IPFR policy:

<https://openrepository.awttc.org/app/serve/resource/ttxe4947>

Or the WHSCC have a patient information leaflet:

<http://www.whssc.wales.nhs.uk/sitesplus/documents/1119/AW%20IPFR%20Patient%20Leaflet%20-%20pdf.pdf>



Further questions?

If you have any further questions about Individual Funding Requests then you can contact our Campaigns and Advocacy team. They are available Monday to Friday from 9:00am – 5:30pm. If you would like to speak to them, you can:

- Call our office line on 01905 755977
- Send them an email at advocacy@leukaemiacare.org.uk
- You can also call the 24-hour CARE Line, free of charge on 08088 010 444. The team will pass your enquiry onto the Campaigns and Advocacy team.

Please note that our Campaigns and Advocacy team are unable to provide:

- Detailed medical advice or recommendations
- Legal advice
- Advocacy for a course of action which is contrary to the aims and objectives of Leukaemia CARE