Blood and Lymphatic cancers
Leukaemia CARE
supporting a quality of life

Advocacy Toolkit:

Individual Funding Requests (IFR) – England

What are they?

Individual funding requests (IFRs) are the NHS England procedure for an individual to gain access to funding for services or treatments not routinely provided by the NHS. They are granted for patients who can demonstrate that they are 'clinically exceptional' and that there is significant evidence that the treatment they are requesting could be beneficial to them and cost effective for the NHS.

Why aren't treatments routinely available to patients?

All new treatments undergo a health and technology assessment (HTA) by NICE (National institute for health and care excellence). They determine whether there is evidence that the treatment is clinically effective and whether there is value for money in supplying it. You can read more about HTAs in the advocacy toolkit.
An IFR may be necessary if:

- A treatment has only recently been developed and a HTA has not yet been carried out.
- NICE have approved the drug for use under certain clinical conditions and the patient does not meet the criteria. For example, the drug may be approved for the treatment of a different condition.
- NICE have not approved the use of the treatment.

Who can apply?

Patients cannot apply for an IFR themselves. It is only clinicians (doctor or other healthcare professional) who can apply for an IFR on behalf of the patient.

Clinical exceptionality

For a patient to be clinically exceptional, clinicians must present the case that their patient is different to all other patients with the same condition and there is a unique set of circumstance as to why they would benefit from access to a particular treatment.

The example that NHS England use is:
"Dental implants are not routinely offered by the NHS, however if a patients could not use their arms due to a disability and needed dental implants to hold a pen so they could write, this might be considered an exceptional case."

Patients will become a cohort if more than one IFR is made for the same treatment and the patients are similar in clinical circumstances or it is likely that they will respond to treatment to a similar degree. This means that they are not clinically exceptional and the IFR will be refused. Instead a request for service development will be initiated to assess whether the treatment should be made routinely available.

The Process

Application sent to NHS England

- Written support and evidence provided by medical staff involved in patient's treatment

Screening process

- Check that the written support has sufficient detail.
- Identify whether the case is clinically exceptional
- Identify if there is arguable basis that the case meets all criteria i.e. that it is cost effective to the NHS.

Decision on application

- Urgent requests are dealt with within two weeks
- Other applications may take up to four weeks

Application approved

- If the application is approved patients can get access to treatment - funded by the NHS.
- In certain cases there may be a set time limit on the funding

Application Rejected

- There is an allowance of 28 days to request a review on how the decision was made.
- If a patient cannot access treatment via IFR there are other options

What options do you have if an IFR 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.

How likely are IFRs to be accepted? Case study Ponatinib

Ponatinib is a tyrosine kinase inhibitor (TKI). Tyrosine kinase is a chemical messenger that drives the growth of cancerous cells and the drug blocks the production of this.

Between April 2013 and March 2015 the drug was only available for CML or ALL patients with a specific gene mutation (T315I). For any other patient to access the drug, their clinician had to submit an IFR.

During this time 14 IFR applications were made and only 2 were passed.

Fortunately, this June (2017) NICE have released final guidance on the use of ponatinib for a wider selection of patients including those who have developed resistance to, or who are intolerant to, dasatinib or nilotinib and people in different stages of their leukaemia .

More information

The NHS England policy can be found in section B of the following document:

https://www.engage.england.nhs.uk/consultation/af642939/supporting_documents/genericcommissioningpolicies.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