



# Advocacy Toolkit:

## Individual Funding Requests (IFR) – Northern Ireland

Correct as of July 2017 – there is a new IFR process that is undergoing consideration and may be implemented soon. Details will be updated accordingly in due time.

### What is an IFR?

Individual funding requests (IFRs) are the Northern Ireland Health and Social Care Board (HSCB) process for an individual to gain access to funding for services or treatments not routinely provided. For approval, there must be evidence to demonstrate the individual patient is “clinically exceptional”, compared to the population of patients with the same condition.

### Under what circumstances are treatments not routinely provided?

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.

An IFR may fall under one of the following categories:

- 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 but not that of the patient.
- NICE have not approved the use of the treatment.

Please note: Northern Ireland is a small geographical region and providing the treatment may not be cost effective. NICE may have approved a treatment, but it has not been endorsed for use in Northern Ireland. In this instance, there is a separate process for gaining access to treatment – extra-contractual referral (ECR).

### 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 there must be an effective response to the question: “On what grounds can the HSC (health and social care) Board justify funding treatment for this patient when others from the same patient group are not receiving the same treatment”.

Responses will be considered, with evidence, to demonstrate the following:

- The patient’s clinical circumstances are different to at least 95% of patients with the same condition at a similar stage of progression.

**AND**

- The treatment being requested will benefit the patient significantly more than would normally be expected.

NB: It is only clinical circumstances that are considered and not personal or social considerations (age, dependents or occupation etc.).



## The Process

### Application sent to the HSCB

- Standard template to be used for submission
- Anonymised submission
- Evidence must be included to support submission
- Application should be endorsed by relevant healthcare trust of the patient

### Consideration by the HSCB panel

- The panel meet weekly to consider applications from the prior 7 day period
- The panel consists of: the assistant director of public health, specialist consultant in public health, assistant director of specialist services committee, a HSCB pharmacist, and a doctor in training public health
- If they require more information the IFR will be reconsidered at a later meeting

### Decision on application

- A decision from the panel will be made within a week of IFR submission
- A record of the decision and rationale will be completed  
An email confirming the decision will be sent to the clinical director of the relevant trust within a week of the HSCB panel meeting

### Application approved

- If the application is approved patients can get access to treatment - funded by the NHS

### Application Rejected

- Clinicians can submit new or additional evidence for reconsideration of the IFR.
- Clinicians can request a review of the panels decision within 20 working days if s/he believes that:
  - 1) The HSCB has failed to follow the IFR policy
  - 2) The decision is irrational in light of the evidence
  - 3) The HSCB has exceeded its powers
- The review panel members are different to those on the HSCB panel

In the case where a patient requires immediate treatment, a consultant can commence treatment following their trust protocols. An IFR will then be considered in retrospect and the prior emergency initiation of the treatment will not prejudice the IFR panel decision.



## How likely are IFRs to be accepted?

IFRs in Northern Ireland show remarkably high levels of acceptance. Between 2012 and 2015 there were 436 requests for oncology and haematology service and of these 378 were approved. Thus, the acceptance rate over a three year period was 87%.

## What options do you have if an IFR is rejected?

### Compassionate use (Early Access Programme)

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.

## More information

The current policy for IFR in Northern Ireland can be found at the following link:

<http://www.hscboard.hscni.net/download/PUBLICATIONS/TRAVEL%20OUTSIDE%20NI%20FOR%20TREATMENT/Requests-for-Care-or-Treatment-on-behalf-of-Individual-Patients.pdf>

The new IFR process, currently under consultation, can be found here:

<https://www.health-ni.gov.uk/sites/default/files/consultations/health/Draft%20Policy%20Document%20%20Individual%20funding%20request%20-%20Final%20for%20Web%20-%202025-Jan-17.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](mailto: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