Classification: Official

Publication reference: PR2085



Individual funding requests for specialised services: a guide for patients

12 June 2023, Version 2

Specialised services provide treatments for patients with a range of rare and complex conditions.

As medical technology advances, a large number of new treatments become available every year – including drugs, medical devices and new surgical techniques.

Some of these are introduced into the NHS in response to guidance from the National Institute for Health and Care Excellence (NICE), while others are brought in after NHS England has evaluated them and found that they are both clinically effective and that they offer the best value for patients and taxpayers. More information on this process is available on our website: www.england.nhs.uk/commissioning/spec-services/key-docs/#ifr

The NICE website has more information on their guidance.

In some cases, it may be possible to fund a treatment for an individual patient outside of the process described above. This is called an individual funding request or IFR.

This individual funding request process applies to the services NHS England directly commissions or remains the accountable commissioner for.

If the treatment or service is paid for by your local integrated care board (ICB) that organisation will consider the request through its own local process.

If you're unsure which organisation your funding request has been sent to, contact the clinician, doctor or other health professional who made the request.

What is an individual funding request?

An individual funding request application can be made by the clinician treating you, if they believe that because your clinical circumstances are exceptional, you may receive benefit from a treatment or service that isn't routinely offered by the NHS.

Why are some treatments not routinely offered by the NHS?

There may be some cases where a treatment is not available because there is limited evidence that demonstrates how well it works or because it has a very high cost and doesn't offer good value for money for taxpayers and the NHS.

When can an individual funding request be made?

An individual funding request application can be made for a treatment that is not routinely offered by the NHS:

- when there is evidence of clinical exceptionality:
 - o when there is no policy in place that gives access to an intervention for a group of patients with your clinical circumstances, that your clinician believes there are no other patients with similar clinical circumstances who might benefit from the treatment in a similar way

OR

- o when there is a policy in place that gives access to an intervention for a group of patients and you do not meet that policy criteria. Your clinician believes that your clinical circumstances are clearly different from other patients with the same condition who do not meet the criteria and there is a reason why you would respond differently to other patients with the same condition who do not meet the criteria - and therefore gain more clinical benefit from the treatment
- and, there is evidence of clinical effectiveness of the requested treatment for your condition
- and, the requested treatment will be a good use of NHS resources.

Examples of clinical exceptionality

A patient had a common condition which normally has mild symptoms, but this patient was experiencing more severe symptoms than other patients with the same condition. The severe symptoms were not normal for that condition. The patient's doctor was able to demonstrate that the impact of those severe symptoms on this patient was very different to other patients with the same condition, and, that the requested treatment would benefit the patient.

A patient had a condition which had a recognised treatment available but the patient's doctor advised that the patient did not meet the criteria in the NHS policy to access the treatment routinely. The patient's doctor submitted an application to demonstrate that this patient was different from other patients with the same condition because of a combination of clinical conditions, and that because of this combination the patient would receive more benefits than other patients with the same condition.

A patient who had previously received a kidney transplant was also being treated for an autoimmune disease. The patient's doctor requested a new treatment which wasn't routinely available to patients with this disease. The doctor requested the new treatment because they had found that the patient had a genetic mutation which indicated that the new treatment would be much more effective for this patient than others. The patient's doctor was able to demonstrate that this mutation hadn't been found in other patients with the condition. The doctor was also sure that the new treatment would put less stress on the kidneys. The patient's genetic mutation together with the improved kidney protection meant that this patient was not in a group of patients who could need it as a routine treatment.

What does my clinician need to explain?

In the application, your clinician will need to explain why your clinical circumstances are different and show all available clinical evidence for why they believe you would benefit more from the treatment than other patients with the same condition. They will also explain to you why they believe that a treatment that is not routinely offered by the NHS is the best treatment option for you.

Patients understand their symptoms better than anyone and may be very well informed on their condition. If you're aware of a treatment that you think may help you, discuss it with your clinician who can advise you if an individual funding request would be appropriate. If there are likely to be other patients with similar clinical circumstances who might benefit from the treatment in a similar way, your clinician can request that NHS England consider introducing it as a routine treatment. If it is approved, the clinician can then make the treatment available to you.

Does the individual funding request process take into account any other patient circumstances apart from clinical exceptionality?

Every person has the same rights to treatment under the NHS no matter what their social, family or other circumstances are. For this reason, it's important that non-clinical factors are not considered in IFR decision making. For example, factors such as the effect of a treatment on a patient's ability to work or study, care for dependants, or meet financial commitments can't be considered as part of the IFR process. The decision is based on clinical circumstances only, which ensures the IFR process is fair, equitable and nondiscriminatory.

Who can make an individual funding request?

The individual funding request application is made by a clinician. NHS England cannot accept individual funding requests directly from patients, although patients can work with their clinician to have input into the process if their clinician believes they are eligible.

Who considers the application?

Your application will first go through a screening process by NHS England to make sure all relevant information has been submitted and the application meets the criteria for an individual funding request (IFR).

If the application meets the criteria for an IFR, it will then be considered by an independent panel who have not been involved in your treatment. The Panel is made up of doctors, nurses, public health experts, pharmacists, NHS England representatives and lay members and is led by a lay independent Chair. The Panel will consider the application in detail before

making a decision, usually within a few weeks. All Panel members regularly receive training to enable them to assess individual funding requests fairly and thoroughly.

Treatments agreed through the IFR process must be funded from the same budget available for other established treatments. It's because of this that every single case is considered extremely carefully before a decision is taken to fund a treatment for an individual that is not usually available on the NHS.

Your personal details will be kept confidential. NHS England will let your clinician know the outcome of the funding request.

If your application is unsuccessful, your clinician will discuss with you the reasons for the decision and what other treatment options may be available.

How long will an application take?

As long as all the required information is submitted, it usually takes 30 working days from receiving an application to a decision, but it can often be sooner. Urgent cases, for example where significant or irreversible loss of function is likely to occur, can be processed more quickly if needed.

How can I find out how my application is progressing?

NHS England will keep in contact with your clinician during the application process and let them know how the application is progressing and if there are any delays. You should therefore speak to your clinician in the first instance.

If you feel your application hasn't been considered within the timelines set out above, you can get in touch with NHS England's Customer Contact Centre for an update. Contact details are below.

Telephone: 0300 311 22 33

Email: england.contactus@nhs.net

Post: NHS England, PO Box 16738, Redditch, B97 9PT

Please ensure you provide your full name, address and date of birth. Your request will be passed to the Individual Funding Request team who will respond as soon as possible.

What do I do if I disagree with the decision?

If the IFR Panel hasn't supported funding for a requested treatment, or if it has approved a treatment subject to conditions and you don't agree, you should speak to your clinician who

may be able to request a review of the decision. The review can be requested if you and your clinician think that the process hasn't been followed correctly, the review must be made within 28 days of when you were informed of the decision.

If your situation changes or more clinical evidence becomes available about the effectiveness of your treatment your clinician may also submit additional information which will be considered.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact england.contactus@nhs.net