



Individual funding requests

This leaflet tells you what happens when you and your Consultant think that you might benefit from a treatment or service that is not usually funded by the Committee for Health and Social Care.

Every year, the Committee for Health and Social Care (CHSC) receives money to pay for health and social care. The CHSC has the difficult task to get the best value for money by spending it wisely on behalf of the people of Guernsey.

Demand for health care is ever growing and new and often expensive treatments are becoming available all the time. However, the CHSC has only a limited amount of money available to spend, so difficult decisions have to be made.

The priority of the CHSC is to pay for treatments and services that demonstrate both improvements to people's health and at the same time offer good value for money for the taxpayer.

As a result there are some treatments and services that the CHSC does not normally make available or are only funded when certain conditions are met. This leaflet explains how your doctor can ask the CHSC on your behalf to support a treatment for you that is not normally provided.

How does the CHSC make funding decisions?

The CHSC endeavours to make these difficult choices in a way which is fair and consistent. In order to do so it is important that the CHSC considers all treatments and services that could potentially be provided against the funds available.

The Individual Funding Request ('IFR') process forms part of the procedure in which decisions are made on which services and treatments to prioritise. The CHSC will always have to make a choice between funding the needs of an individual patient against funding services or treatments for a larger group of patients.

When can an IFR be made?

Your Consultant can make an application to the IFR Panel if they consider that there are *exceptional* circumstances which might justify making a treatment currently not provided available to you. In most instances this will mean making a case for treating you when other patients who appear similar to you do not get access to that treatment or service. The Panel also deals with some requests to enter patients into a clinical trial where CHSC is expected to bear the costs of the clinical trial or any funding issues after the trial has finished.

What happens when an IFR application is received?

When an IFR is received it will be assessed to determine whether or not it qualifies for consideration. This is referred to as the screening process. The qualifying conditions are set out in CHSC policy G1002: *'Individual Funding Requests'*. A copy can be requested from the Off Island Team (currently the document is not available on the website). An application might be rejected at this stage because it does not meet all the conditions or because there is insufficient information to make a decision.

If the request qualifies it will be referred to the IFR Panel for consideration. To ensure fairness, every request is dealt with in the same way and personal details are removed from all the paperwork so that the Panel are unaware of the identity of the patient. The Panel meets monthly, although urgent requests can be dealt with as the circumstances may require.

What can I do if my request does not get past the screening stage?

If a decision is made that your application is not to be put to the IFR Panel your Consultant and your General Practitioner (if we have that information) will be informed that is the case, together with the reasons for that decision. If the reason is because insufficient information has been provided, the application can be resubmitted with further additional information for reconsideration.

How does the IFR Panel work?

If your application is forwarded to the Panel it will be considered at the next Panel meeting, unless clinical circumstances indicate that a quicker decision is needed.

Unless the decision needs to be made urgently for clinical reasons, you will get a letter informing you that your application has been referred to the IFR Panel. This will tell you how you can also submit additional information to the IFR Panel.

The Panel is made up of a number of health professionals and a lay member. The Panel considers the request against an agreed set of criteria and policies to ensure the decision making is fair, consistent and transparent.

The Panel considers, amongst other things, whether the treatment is likely to be beneficial and is safe ('clinical effectiveness'), how much it will cost to achieve the health benefit predicted ('value for money' and 'cost-effectiveness'), and the cost of treatment in relation to the total budget and other health care needs which CCHSC is not able to currently fund ('affordability').

The Panel can only authorise cases when the total cost of treatment is less than £30,000. Above that figure the Panel makes a recommendation for consideration by CHSC outside of the Panel. CHSC will then consider whether or not funding the treatment is affordable against other potential competing demands for health care.

Can I or a clinician attend the IFR Panel in person?

No. Only IFR Panel members may be present. However, all the written evidence will be carefully considered before decisions are made.

What does 'exceptional' mean?

What is exceptional does not relate to your personal or family circumstances, as if it did, every case would of course be exceptional and every case has compelling and unique personal factors which apply. What is meant by *exceptional circumstances* is (amongst other things):

- There are clinical features that make you significantly different from others who have the same or a similar condition AND you are likely to obtain substantially more clinical benefit from receiving the desired treatment when compared to other patients with the same or a similar condition.
- Your case justifies breaching the important principle of equality in treatment.
- Your case is so rare that it is reasonable to fund an experimental treatment outside of a clinical study.

How will I find out the outcome of my application?

The Panel will write to you informing you of the Panel's decisions and will give you reasons for the decision that was reached. A copy will also be sent to your Consultant and General Practitioner (if we have your GP's details). This letter will also give contact details if you wish to have the decision reviewed. Your doctor will discuss the implications of the decision with you.

What can I do if the request is not funded?

In the first instance you should talk to the doctor who made the application on your behalf. Your doctor should agree a new management plan with you going forward.

You and your doctor can ask for a review of the IFR Panel's decision on the following grounds:

- The CHSC failed to follow its own policy and processes and, as a result, the decision reached by the Panel was different from the one that would have been otherwise reached.
- The IFR Panel did not take into account all the relevant evidence when making its decision.

The request for a review must be made in writing to the Chief Secretary of the CHSC within 20 days of the date of the letter in which you were told the decision of the IFR Panel. The CHSC may, in their discretion, accept requests outside this time limit if there are good reasons for the delay.

If the CHSC does not accept the grounds put forward for a review, a letter will be sent to you and your consultant explaining the reasons. A copy of this letter will be sent to your GP if we have his or her details.

If the CHSC accepts the grounds put forward then a Review Panel will be convened.

To ensure a fair process, reviews are considered by different people from those who made the original decision.

You will receive a letter informing you that your application has been referred to the Review Panel.

The Review Panel will not consider new clinical evidence. If new evidence becomes available your Consultant should make a new IFR submission.

The Review Panel cannot overturn the decision of the IFR Panel. However, if the Review Panel decides that the decision was not reached correctly, then it can instruct the IFR Panel to reconsider your case.

What if the IFR Review Panel supports the original decision?

You have no further right of appeal through the IFR procedure.

What if there is new information I think the IFR Panel should have been aware of?

Your Consultant, in discussion with you, can submit new information regarding your medical condition or the treatment you wish to have at any time. If it is considered that this new information might have changed the original decision, if it had been available when that case was considered, then the case will be referred back to the IFR Panel for further consideration.

Complaints

If you are dissatisfied with the way in which your case has been handled you are entitled to make a complaint under the CHSC's Complaints Procedure details of which can be found on the website shown below. However you cannot challenge the funding decision itself through the complaints process.

Details of the CHSC's complaint procedure can be obtained from the Off Island Team

FAO: Individual Funding Requests
The Off Island Team
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