

**Appendix E: Information Leaflet**

NHS Mid-Essex CCG has a duty to spend the money it receives from the Government in a fair and efficient way, taking into account the health needs of the whole local community.

As there is only a set amount of money available to spend we sometimes have to make difficult decisions about which treatments are routinely provided.

In some circumstances, your clinician (usually a GP or consultant) may think you have **exceptional clinical circumstances** and may benefit from a treatment which is not routinely provided.

Requests for such treatments must be made through an Individual Funding Request (IFR).

When can an Individual Funding Request (IFR) be made?

There are two situations when it is possible to make an IFR:

- When the CCG does not have a policy stating who is eligible for the treatment that is being requested
- When the CCG has a policy -but your clinical circumstances do not meet the policy's definition of who is eligible for the treatment.

In either circumstance, your GP or consultant will need to demonstrate that your clinical circumstances are **'exceptional'** and justify treating you when others would not get the treatment

INDIVIDUAL FUNDING REQUESTS

Information for patients in Mid-Essex CCG

This leaflet tells you what happens when you and your GP or Consultant think that you might benefit from a treatment that is not usually available on the NHS.



What does 'exceptional' mean?

In deciding whether your clinical circumstances are 'exceptional' the CCG will consider two questions:

- Are there any clinical features that make you significantly different from others who have the same clinical condition?
- Are you likely to obtain significantly more clinical benefit from receiving the desired treatment when compared to other patients with the same condition?

Social factors are not considered as part of the IFR process.

Who can make an Individual Funding Request?

If your GP or Consultant agrees that a treatment would be of benefit to you, and that there are no alternative treatments or services available for your condition, they can then make a request to the CCG on your behalf but only if they consider your individual circumstances are exceptional.

Requests are made on a form which asks questions that allow your GP or Consultant to describe your personal clinical circumstances, how they think the treatment will specifically benefit you, the evidence that it is both safe and effective, the cost of the treatment and how commonly your condition occurs in the community.

How is an IFR managed?

The CCG follows the same procedure for every IFR to ensure we act fairly. All requests are treated in strict confidence and we remove your personal details from all paperwork.

When we receive a request, a check is made to ensure no service or treatment exists locally. If treatment is available then we will inform your GP or Consultant so they can discuss it with you.

If there is no service or treatment then the request is screened by a clinician and the CCG's IFR Coordinator to decide whether the conditions for being considered 'exceptional' have been met. A decision will normally be sent to your GP or consultant within ten working days (copied to you and your GP) unless the form is incomplete or more information is needed.

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

If your clinical circumstances are not considered to be exceptional you have the right to complain through the CCG complaints process. The complaints process will not review whether the screening decision was correct, but will check that the IFR policy was correctly followed.



How does the IFR Panel work?

If the screening team agrees that there are grounds to consider your request as exceptional, your case will be considered by the CCG's IFR Panel within 20 working days of the screening decision, unless the clinical circumstances indicate that a quicker decision is needed.

The panel is made up of health professionals, lay members and CCG managers who consider the request against an agreed set of criteria to ensure the decision making is fair, consistent and transparent.

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01245 398 740/01245 398 106

The panel reviews whether the treatment is likely to be beneficial and is safe (known as 'clinical effectiveness'), how much it will cost to achieve the health benefit that is predicted (known as 'cost effectiveness') and the cost of the treatment in relation to the total CCG budget for providing health care (known as 'affordability').

How will I find out the outcome of my request?

The panel will write to your GP or consultant informing them of the panel's decision within five working days of the panel meeting giving the reasons for the decision that was reached. You will also be sent a copy of the letter.

What can I do if the request is not funded?

In the first instance you should speak to your GP or consultant. You and your GP or Consultant can ask for a review of the IFR Panel's decision on the following grounds:

- The IFR Panel failed to follow due process and, as a result, the decision reached by the panel was different from the one that would be reached if due process had been followed.
- The IFR Panel did not take into account, or weigh appropriately, all the relevant evidence when making its decision.

The request for a review must be made in writing to IFR Co-Ordinator of the CCG within 20 working days of the date of the IFR Panel's decision letter. The CCG may accept requests outside this time limit if there are good reasons for the delay.

If the CCG **does** accept the grounds put forward then a Process Appeal Panel will be convened. To ensure a fair process, all reviews are considered by different people from those who made the original IFR decision.

If the CCG **does not** accept the grounds put forward for a review, a letter will be sent to the referring GP or Consultant explaining the reasons.

The Process Appeal Panel will not consider new clinical evidence. If new evidence becomes available your GP or Consultant should make a new Individual Funding Request submission.

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

**Can I, or a clinician, attend the IFR panel in person?**

Yes. You or your clinician may attend and present your case to the panel. The information provided by you, or your clinician, at the panel, in addition to the written evidence provided, will be carefully considered before decisions are made.

Can I, or a clinician, attend the Process Appeal Panel in person?

No. Only members of the panel may be present. The panel will review the process using written records of the original IFR panel.

What if the Review supports the original decision?

You have no further right of appeal through the IFR procedure but you may make a complaint about the handling of your request by NHS Mid-Essex CCG at any time. Details of where to submit your complaint can be found on the back page of this leaflet.

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

Your GP or consultant, in discussion with you, can submit new information regarding your medical condition or the treatment you are requesting at any time. If the Medical Director and the CCG's IFR Co-ordinator consider that this information might have changed the decision that was previously reached by the CCG then the case will be reconsidered following the process outlined above.

Do I have to pay a fee to make an Individual Funding Request or an appeal against a decision?

There are no fees payable to the CCG for any part of the Individual Funding Request process.

To whom should I address my complaint?

Your complaint should be submitted in writing to: Patient Advice Liaison Service (PALS) and Complaints, NHS Mid-Essex CCG, Wren House, Hedgerows Business Park, Chelmsford CM2 5PF

If you choose, you can also write to the Health Service Ombudsman at:

The Parliamentary and Health Service Ombudsman

Millbank Tower

Millbank

London SW1P 4QP

Where can I get further advice and support?

If you wish to find out about the progress of an IFR request which is already being processed by the CCG please contact the IFR Co-ordinator at meccg.ifr@nhs.net or by writing to us at IFR Dept, NHS Mid-Essex CCG, Wren House, Hedgerows Business Park, Chelmsford CM2 5PF