

Appendix D: Guidance notes for Clinicians

1. How should I decide whether to make an Individual Funding Request?

The criteria on who is eligible to be considered as an Individual Funding Request have been clarified by the IFR policy and will now be applied consistently across the CCG. The key consideration is whether the treatment that you wish to request for your individual patient will meet the definition for '*exceptional clinical circumstances*' that is set out in the policy.

2. What is meant by 'exceptional clinical circumstances'?

The CCG cannot fund requests that should be fairly applied to other patients who have similar clinical circumstances and who should rightly also be offered the treatment if your patient was to be approved. This would require the CCG to agree a new commissioning policy (or amend an existing one) setting out that the treatment was now available for a new group of patients and setting out how this group had been identified. Therefore, to meet the definition of 'exceptional clinical circumstances' you must demonstrate that your patient is both:

- Significantly different clinically to the group of patients with the condition in question and at the same stage of progression of the condition e.g. metastatic bowel cancer not just bowel cancer.

AND

- Likely to gain significantly more clinical benefit than others in the group of patients with the condition in question and at the same stage of progression of the condition

In other words, you must show that your patient is very different from others in group of patients with the same condition/stage of the disease and has clinical features that mean that they will derive much more benefit from the treatment you are requesting.

3. What is meant by rarity?

For the purposes of this policy, an Individual Patient is defined by the incidence and prevalence of the requested intervention for a particular condition at the same stage of progression. Incidence is the number of new cases of a disease in a defined population within a specified period of time.

In order to satisfy the incidence criterion, the intervention for a particular condition at the same stage of progression as that of the Individual Patient is expected to be initiated for not more than three patients per million population per year (i.e. 3 patients across the CCGs' population per year).

Prevalence is the number of cases of a disease in a defined population at a particular point in time. In order to satisfy the prevalence criterion, the total number of patients in receipt of the intervention for a particular condition at the same stage of progression as that of the Individual Patient should not be more than ten patients per million population at any one time (i.e. 10

patients across the CCGs' population).

4. Why are only clinical features taken into account?

The CCG must make decisions fairly about funding treatments and not on the basis of age, sex, sexuality, race, religion, lifestyle, occupation, family status (including responsibility for caring for others) social position, financial status etc. unless these directly affect the expected clinical benefit that an individual will derive from a treatment e.g. the effect of the increasing age of a woman on fertility.

5. How do I make an Individual Funding Request (IFR)?

All requests must be made on a standard treatment request form which can be obtained electronically from ifr.northants@nhs.net. It is the responsibility of the referring clinician to ensure that the form is completed accurately by seeking specialist information from other clinicians as required.

The form aims to ensure that all the necessary information is obtained so it is important that it is completed comprehensively and accurately, along with any relevant research papers, by the referring clinician to avoid delays in reaching a decision. The form can either be returned electronically or by post.

6. How can I get advice on what to include when completing a treatment request form?

You can telephone or e-mail the IFR department on 0121 611 0644 or email ifr.northants@nhs.net for advice on whether to submit a treatment request form and what to include.

7. Who will make the decision on whether the Individual Funding Request (IFR) is approved?

All new Individual Funding Requests are 'screened' by a Public Health Specialist and a Commissioning Manager to decide whether "exceptional clinical circumstances' have been demonstrated. If there is no evidence of exceptional circumstances (often because the patient is clearly part of a definable cohort) then the request is declined at this stage. If evidence of exceptionality is presented, or if the screeners are uncertain whether the case is exceptional or not, then the case will be forwarded to the CCG IFR Panel. The panel will include a CCG lay member, Executive Director, Public Health Specialist and a GP Clinical Chair. They will determine whether there is a case for exceptionality and whether the intervention is safe and clinically and cost-effective.

8. How will I be informed of the CCG decision?

You will receive a letter informing you of the decision of the screening of your request within 20 working days of receipt of your treatment request form. If your request is being taken to the CCG Panel will be informed of the date of the panel, usually within a further 20 working days, and will receive a letter outlining the decision of the panel within 5 working days after the panel meeting.

9. How will my patient be informed of whether the request has been approved?

All correspondence will be copied to the patient and to their GP if they are not making the request.

10. Can either the patient, or a clinician involved in their care, attend the panel?

No. The panel will only consider the written evidence that has been submitted so it is very important that all the evidence is presented in your treatment request form.

11. Can I or my patient appeal, against the CCG decision?

There is no right to appeal against the decision at the 'screening' stage although it is possible to complain under the CCG Complaints Policy. However, this will not overturn the decision of the screening stage but will examine whether the policy was properly followed. If the CCG panel does not approve your request you, or your patient, are entitled to appeal and ask for a review of the process that was undertaken by the CCG. The Appeal Panel will decide if the CCG followed the correct procedures and the CCG Panel reached a decision that was rational and based on all the evidence that was presented.

12. What can I do if my patent is not exceptional e.g. represents a group of patients in similar clinical circumstances

If you disagree with an existing policy then you can try to change it but this can not be achieved through the IFR process. If the treatment or services is covered by CCG, it will need the support of all the relevant clinicians through a clinical network, if one exists, or by a direct approach to the CCG.

Please note that it would be unusual to introduce a new development in year as each year resources are already committed through an annual round of prioritisation. Hence new developments will usually require reallocation of resources from existing services.