POLICY AND OPERATING PROCEDURES FOR DEALING WITH INDIVIDUAL FUNDING REQUESTS

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EQUALITY IMPACT ASSESSMENT TOOL

To be completed and attached to any procedural document as part of main document sited between version control sheet and contents page

		Yes/No	Comments
1.	**Does the document/guidance affect one group less or more favourably than another on the basis of:**		
	• Race	No	
	• Ethnic origins (including gypsies and travellers)	No	
	• Nationality	No	
	• Gender	No	
	• Culture	No	
	• Religion or belief	No	
	• Sexual orientation including lesbian, gay and bisexual people	No	
	• Age	No	
	• Disability - learning disabilities, physical disability, sensory impairment and mental health problems	No	
2.	**Is there any evidence that some groups are affected differently?**	No	
3.	**If you have identified potential discrimination, are there any exceptions valid, legal and/or justifiable?**	N/A	
4.	**Is the impact of the document/guidance likely to be negative?**	No	
5.	**If so, can the impact be avoided?**	N/A	
6.	**What alternative is there to achieving the document/guidance without the impact?**	N/A	
7.	**Can we reduce the impact by taking different action?**	N/A	

For advice in respect of answering the above questions, please contact Tina Gull Equality and Diversity Lead E-mail: Tina.Gull@surreypct.nhs.uk Telephone 01932 723543 If you have identified a potential discriminatory impact of this procedural document, please contact as above.

Names and Organisation of Individuals who carried out the Assessment: Please give contact details	***Date of the Assessment***
T Gull, P Byne, E Stevens NHS Surrey	12.11.09
S Lewis-Jones Surrey Coalition of Disabled People	

VERSION CONTROL SHEET

Version	Date	Author	Status	Comment
1	April 2008	Public Health	Final	Agreed at PEC and PCT Board
2	Oct 2008	Public Health	Final	Minor amendments to application form agreed at PEC 8/10/08. Also minor amendments to the wording in relation to High Cost Drugs in the section on Scope of Policy, Remit of Exceptions Panel and contract details. Also revision of Membership of High Cost Drugs Panel.
3	Jan 2009	Public Health	Draft	Major amendments to the wording in relation to guiding principles, definition of exceptional circumstances, appeals process and high cost drugs panel. Evidence based amendments to the referral criteria for reduction mammoplasty, male breast reduction for gynaecomastia, augmentation mammoplasty, revision of breast augmentation, mastopexy, nipple eversion, pinnaplasty, external ear lobule repair, alopecia, hair transplantation, abdominoplasty, lipoma and skin lesions, tattoo removal, hair depilation, scar revision, gender reassignment, grommets, bone anchored hearing aid, cochlear implants, HBOT, weight loss, TAVI, dental implants, gastric surgery Revision of Exceptions Panel process flowcharts Terms of reference for Exceptions Panel
3	Sept 2009	M. Hatch, A. Ali, L. Brutus	Draft	Amendments made to the IFR intervention process
3	Sept 2009	Liz Taylor	Draft	Minor amendments to process Ratified by R&CG
3	Oct 2009	M. Hatch, A. Ali, M. Baker	Draft	Minor amendments and clarification of terminology used, addition of Intervention triage meeting TOR

3	Oct 2009	Ruth Milton	Draft	Minor amendments following clarification of the appeal panel TOR
3	Nov 2009	Kiran Bhogal Linda Honey	Final	Minor amendments to terminology used and process and minor amendments following Equality Impact Assessment feedback

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EQUALITY STATEMENT

NHS Surrey aims to design and implement services, policies and measures that meet the diverse needs of our service, population and workforce, ensuring that none are placed at a disadvantage over others. It takes into account the Human Rights Act 1998 and promotes equal opportunities for all. This document has been assessed to ensure that no employee receives less favourable treatment on grounds of their gender, sexual orientation, marital status, race, religion, age, ethnic origin, nationality, or disability.

Members of staff, volunteers or members of the public may request assistance with this policy if they have particular needs. If the member of staff has language difficulties and difficulty in understanding this policy, the use of an interpreter will be considered.

NHS Surrey embraces the four staff pledges in the NHS Constitution. This policy is consistent with these pledges.

1 INTRODUCTION

The South East Coast (SEC) Health Policy Support Unit (HPSU), acting on behalf of the PCT Alliance, produced the following documents:

- The South East Coast Primary Care Trusts Principles and Guidance for dealing with Individual Funding Requests
- South East Coast Primary Care Trusts Model Policy and Operating Procedures for dealing with Individual Funding requests

These documents were designed to help PCTs develop systems in relation to individual funding requests (IFRs) which will facilitate the adoption of area-wide standards and procedures operating in accordance with the requirements of current national guidance (NHS Constitution for England Jan 09, Directions to primary care trusts and NHS trusts concerning decisions about drugs and other treatments March 09 Department of Health, Defining guiding principles for processes supporting local decision-making about medicines Jan 09 Department of Health / National Prescribing Centre, Handbook of good practice for local decision-making March 09 National Prescribing Centre).

NHS Surrey has ratified the SEC Principles and Guidance for dealing with Individual Funding Requests document and has based this policy on the SEC Model Policy and Operating Procedures for dealing with Individual Funding requests document.

NHS Surrey has divided the way that IFRs are to be processed, with all panels following the same guidance to ensure consistency in decision making. All drug related IFRs are to be handled by the Pharmaceutical Commissioning Team and considered by the IFR drugs panel and all other interventions are to be considered by the IFR intervention panel. IFRs for mental health placements will be considered by a separate IFR placement panel.

2 IFR PROCESS

2.1 Submission Process

Who can make a submission

IFRs may be submitted by an NHS consultant, a GP or dental practitioner, or an equivalent autonomous practitioner provided s/he will be responsible for administering the treatment ("the requesting clinician"). Patients may not make submissions directly.

Responsibilities of the requesting clinician

- The requesting clinician is required to affirm that s/he has discussed the proposed treatment with the patient (or has offered such a discussion) before the submission is made for funding on his/her behalf.
- The requesting clinician is required to affirm that s/he has made the patient aware of the implications of embarking on the IFR process, the fact that it may take some time before a decision can be made and that if the patient is considering privately funding the requested treatment while the IFR is being considered, retrospective funding will not be available even if the IFR is subsequently approved.
- It is the responsibility of the requesting clinician to ensure that all the information required in support of a submission is submitted.

Submission Form

NHS Surrey has adopted the HPSU produced standardised submission form for IFRs. All funding requests should be submitted on this form (see Appendix 1).

Prior approval is required for ALL individual funding requests. NHS Surrey does not fund retrospectively and the onus is on the requesting clinician to ensure that IFRs are submitted and funding approved before treatment is initiated.

Submissions for drug IFRs

Submissions for drug IFRs must be sent electronically as an attachment to the Pharmaceutical Commissioning team at NHS Surrey highcost.drugs@nhs.net. From the 1st April 2010 submissions must be sent electronically via the web-based database https:\\www.healthlinx.co.uk\hicost-trust (passwords will be provided by the pharmaceutical commissioning team).

The Pharmaceutical Commissioning team will check the highcost.drugs@nhs.net account daily for drug IFRs (and from 1st April 2010 the web-based database).

All submissions will be processed as follows:

1. Form to be completed by requesting clinician (in combination with specialist nurse if appropriate)

2. Completed form to be sent to the Provider Trust's pharmacy department for authorisation. The PCT and the Provider Trusts need to work with clinicians to ensure that only IFRs which can meet the criteria of 'exceptionality' or 'rarity' are submitted to the IFR process.
3. Authorised form to be sent electronically as an attachment to highcost.drugs@nhs.net by the Provider Trust's designated contact(s) (from 1st April 2010 to be sent via the web-based database as detailed above)

Requesting clinicians are advised that failure to use the correct paperwork, to follow the above process or submit the form in the required format may result in a delay in NHS Surrey considering IFRs. Incomplete submissions will not be considered.

IFRs must be received by the Pharmaceutical Commissioning Team at NHS Surrey highcost.drugs@nhs.net (and from 1st April 2010 via the web-based database) five (5) working days before the next IFR drug panel in order for the request to be considered at that panel.

Submissions for Intervention IFRs

Submissions for intervention IFRs must be submitted to the Acute Contracting Treatments Not Routinely Funded (TNRF) team at NHS Surrey either electronically at tnrf@nhs.net. or by post to the team at the following address: Pascal Place, Randalls Research Park, Randalls Way, Leatherhead, Surrey KT22 7TW or by fax to the Safe Haven fax : 01372 202690.

Failure to use the correct paperwork or submit sufficient information may result in a delay in NHS Surrey considering IFRs.

2.2 Receipt of IFR Submission and Triages for Eligibility

- Only submissions using the standardised submission form (Appendix 1) with the required supporting information will be considered by an IFR panel.
- IFRs relating to drugs will be considered by the IFR drug panel.
- IFRs relating to other interventions will be considered by the IFR intervention panel.
- IFRs for mental health placements will be considered by a separate IFR placement panel.

2.3 On Receipt of IFR Submission

On receipt of an IFR submission each form will be checked to ensure that:

- The PCT is the Responsible Commissioner for that patient
- All contact details have been provided
- Relevant parts of the form have been fully completed
- All supplementary documentation referred to is attached

- The submission has been approved by a suitable representative of the Trust providing the treatment (as appropriate)

Submissions for Drugs IFRs

The above checks will be carried out be a member of the Pharmaceutical Commissioning team.

Submissions for intervention IFRs

The above checks will be carried out be a member of the Acute Contracting Treatments Not Routinely Funded (TNRF) team. Providing the IFR fulfils the above the IFR will then be submitted to the next IFR Intervention Triage Meeting.

2.4 Check for Eligibility for Consideration by the IFR Panel

If the submission is not sufficiently complete, the form and any accompanying material will be returned to the requesting clinician within 3 working days of receipt of the form.

Completed forms will be reviewed to check that the IFR is eligible for consideration by the relevant IFR panel by reference to the following questions – whether the treatment requested:

- Is funded within an existing commissioning policy?
- Is covered by another PCT policy or process?
- Amounts to a service development? **

within 3 working days for drug IFRs and 10 working days for intervention IFRs of receipt of the completed form.

If the answers to the above three questions are all negative, then the submission meets the criteria for consideration as an IFR on the grounds that either:

- The patient is suffering from a medical condition or clinical presentation which is considered rare **and** for which the PCT has no policy because the low probability of the condition occurring among the PCT's population means that an explicit policy is not warranted ("A rarity request"), or

- The patient is suffering from a presenting medical condition for which the PCT has a policy but where the requested treatment has not been agreed to be funded under the policy ("An exceptionality request") and the patient's clinical circumstances are considered by the requesting clinician to be exceptional.

** Whether or not a request should be considered as an IFR or as a request for an in-year service development will depend on whether there are one or more other patients within the population served by the PCT who are, or are likely to be, in the same or similar clinical circumstances as the requesting patient in the same financial

year, and who could reasonably be expected to benefit to the same or a similar degree from the requested treatment.

If it is foreseeable that there will be other than one similar patient, then the request should properly be considered as a request for a service development, except in the circumstances where all the anticipated patients are expected to be from the same family group; a situation which may arise in the context of a rare genetic disease. If all anticipated patients are expected to be from the same family group then the request should be considered as an IFR.

Submissions for Drug IFRs

The Head of Pharmaceutical Commissioning (or nominated deputy) will determine if a drug IFR is eligible for consideration by the IFR drugs panel. If the submission is considered a service development the requesting clinician should be advised to contact the Pharmaceutical Commissioning team via highcost.drugs@nhs.net for advice on how to proceed and when a business case is submitted it will be considered by NHS Surrey's Area Prescribing Committee.

Submissions for Intervention IFRs

A bi-weekly triage meeting will be held to determine if an intervention IFR is eligible for consideration by the IFR intervention panel (see Appendix 2 for TOR of the triage meeting).

2.5 Redirection of Requests that are Ineligible for Consideration by the IFR Panel

If an IFR submission is ineligible for consideration by the IFR panel the reason why will be determined and appropriate action taken. The submission will be returned to the requesting clinician (within 3 working days for drug IFRs or within 10 days for intervention IFRs) of the decision being made. At the same time the requesting clinician will either be directed to a more appropriate contact or advised that the request is considered a service development and requires a business case to be submitted to NHS Surrey for consideration.

However, if there is a clear clinical reason why the patient's health will be significantly compromised by waiting until a service development decision has been made then the submission will be processed and taken to the IFR panel and be considered by the IFR panel in the second part of the meeting.

All ineligible IFRs received will be entered onto the appropriate database (NHS Surrey's high cost drugs database / treatments not routinely funded database) noting:

- the date received, the date scrutinised, and the date returned
- the reason why the submission is ineligible
- the nature of the redirection or transfer

- if a service development whether the submission is to be considered by the IFR panel in part 2 of the meeting

The requesting clinician or patient does not have the right to appeal if an IFR submission is ineligible for consideration by the IFR panel and they will be advised if they wish to take the matter further this must be through the NHS Complaints process.

2.6 Dealing with an Eligible Request

2.6.1 Anonymity and IFR Tracking Record

A file for each eligible IFR submission will be created on the appropriate database: NHS Surrey's High Cost Drugs database for drug IFRs / NHS Surrey's Treatments Not Routinely Funded for intervention IFRs. A unique identifier will be assigned to the submission.

The first part of the form (parts 1 and 2), containing the identity of the patient and requesting clinician will be separated. From this point in the process forward the submission form (and all copies) will be anonymised and distinguished only by the identifier, in keeping with Caldicott principles.

All the actions, decisions and reasons for decisions relating to the IFR will be summarised on the High Cost Drugs database or Treatments Not Routinely Funded database.

2.6.2 Acknowledgement

Submissions for Drug IFRs
The requesting clinician will be advised by e-mail that the submission has been accepted by the Pharmaceutical Commissioning Team for consideration at the next panel and informed of the date of the next panel.

All drug IFRs will be considered within 15 working days of receipt of a fully completed IFR form.

Submissions for Intervention IFRs
The Acute Contracting (TNRF) Team will submit IFRs to the IFR Intervention Panel within 28 working days of receipt of a fully completed IFR form.

Where there is likely to be a delay the requesting clinician will be advised of this.

2.6.3 Identification of time limits and potential cost pressures

In respect of each submission received, the submission will be checked to establish whether any time-limited procedures, such as the 18-week rule, apply to each submission and whether any special circumstances exist which may interact with the timing and progress of the IFR process.

Additionally, the PCT finance directorate will be notified of any submissions received which, if approved, are likely to lead to cost pressures. Such notification is not to be taken as an indicator that the submission will be approved.

2.6.4 Call for more information/evidence review/specialist advice

Submissions for Drugs IFRs

Each individual IFR drug submission will be allocated to a member of the Pharmaceutical Commissioning team for processing. The onus is on the Trust, as the experts in the area, to submit all relevant clinical information with the submission.

The Pharmaceutical Commissioning Team will following receipt of the submission routinely perform a literature search (see Appendix 3 for relevant standard operating procedure) to identify relevant clinical information.

It is the responsibility of the member of the Pharmaceutical Commissioning team processing the drug IFR to decide what further information, specialist advice, and/or review of evidence is required to enable the IFR Drugs panel to consider the submission.

Each case is likely to be different and so will be handled on an a case by case basis. When requesting more information the Pharmaceutical Commissioning Team member will make it clear what further information is required and the timeframe within which it should be received.

The member of the Pharmaceutical Commissioning team processing the IFR will make a note of any further information, specialist advice and/or evidence review requested in respect of each submission on the High Cost Drugs database and will take any steps necessary to ensure that the submission is fully complete and all supplementary information has been received prior to circulation of the IFR submission to the IFR drugs panel.

Submissions for Intervention IFRs

If the IFR is for treatment that is new or unusual, the Acute Contracting TNRF Team will ask the Public Health & Clinical Quality Directorate to provide an evidence briefing for the requested treatment.

If an evidence briefing on a new or unusual treatment is required from the Public Health & Clinical Quality Directorate (“the directorate”) this may take up to 10 working days to enable members of that team to access information from diverse sources including published research and expert opinion. The directorate will endeavour to obtain this information prior to the scheduled IFR intervention panel meeting date.

Where the information requested is not available for the next IFR intervention panel meeting date and / or information is sought from external organisations and the view is that insufficient information is available for a decision to be made, consideration of

the intervention IFR may be deferred so as to enable an informed Panel decision to be made**.**

Clinical advice may be sought from PCT clinicians, local consultants and specialist commissioning services. Where a delay may occur this will be conveyed to the requesting clinician.

2.7 Fast-tracking Urgent IFRs

IFRs should only be fast-tracked where there is a clear clinical reason that the patient's health will be significantly compromised by waiting until the next scheduled IFR panel meeting for a decision to be made.

It is expected that only a small minority of IFRs will be fast tracked and these will usually involve life-threatening conditions.

IFRs will not be fast-tracked on grounds that waiting until the next IFR panel is inconvenient or problematic for the patient or requesting clinician.

Before assigning IFRs to the fast-track procedure careful consideration will be given as to whether sufficient information is available for the IFR Panel to make a decision without compromising any of the principles upon which decisions should be made.

A fast-tracked IFR will be considered by a specially convened group ("the group") acting as a sub-committee of the next scheduled IFR panel under delegated powers.

The group will comprise of three (3) members of the IFR panel membership group, and must include one lay member, one person qualified to chair and one member who is clinically-qualified. The group may confer by telephone conference as well as in person.

A fast-track decision will be made by reference to the SEC Ethical Framework and the consensus method for decision-making, as would be the case for regular IFRs and the decisions of the group will be ratified by the IFR panel during its next scheduled meeting.

The decisions available to a group are:

- the request will be funded **without conditions**
- the request will be **funded with conditions** attached
- the request will **not** be **funded**
- a decision cannot be made because more evidence / information is required and the decision is therefore **deferred.**

If the group defer the decision the evidence / information required will be obtained as soon as possible at which point the submission will be re-considered by the group.

Submissions for Drugs IFRs

The Head of Pharmaceutical Commissioning (or nominated deputy) is responsible for managing the fast-track process and the distribution of information/evidence among the group for fast tracked drug IFRs.

S/he is also responsible for communicating the fast-track decision to the requesting clinician (and the patient if appropriate) and for documenting the decision, the reasons behind the decision and the consensus reached.

All information relating to the fast-tracked IFRs (the processed IFR submission form, emails and the decision made) must then be passed to the Pharmaceutical Commissioning team for inclusion in the papers for the next scheduled IFR drug panel meeting for ratification, and for inclusion and updating of the High Cost Drugs database.

Submissions for Intervention IFRs

The Acute Contracting TNRF Manager (or nominated deputy) is responsible for managing the fast-track process and the distribution of information/evidence amongst the group for fast tracked intervention IFR's.

S/he is also responsible for communicating the fast-track decision to the requesting clinician (and the patient if appropriate) and for documenting the decision, the reasons behind the decision and the consensus reached.

All information relating to the fast-tracked IFR (the IFR submission form, emails and the decision made) must then be passed to the TNRF Team for inclusion in the papers for the next scheduled IRF Interventions panel meeting for ratification, and for inclusion and updating of the TNRF database.

2.8 Agenda and Supporting Papers

The IFR panel Agenda will list general business, the submissions requiring consideration, submissions withdrawn, fast-tracked submissions and any other business including part 2 submissions for consideration pre service development.

For each submission requiring a decision, the Agenda should set out:

- the unique identifier
- status (i.e. new submission, second/third consideration of deferred submission, ratification of sub-committee decision, interim report on patient condition following conditional approval, consideration pre service development)
- a list of documents relating to each submission: e.g. submission form, reviews of evidence, statement of specialist advice, statement by patient or others, published articles, second consultant opinion, interim report on patient condition following conditional approval, etc.

IFR Panel members will receive the Agenda and supporting papers no less than 3 working days before each scheduled panel meeting.

If an IFR panel member requests further information or raises a question about the papers in advance of the meeting, both the request/question and the response should be circulated to all IFR panel members as soon as possible.

Submissions for Drugs IFRs
The Pharmaceutical Commissioning team is responsible for all the logistical and administration arrangements for IFR Drug panel meetings. The Pharmaceutical Commissioning team will prepare the Agenda and papers for each drug panel meeting, in consultation with the Head of Pharmaceutical Commissioning as necessary.

Submissions for Interventions IFRs
The Acute Contracting TNRF team is responsible for all logistical and administration arrangements for IFR Intervention panel meetings. The Acute Contracting TNRF team will prepare the Agenda and papers for each intervention panel meeting in consultation with TNRF Manager.

2.9 The Panel Meeting

All IFRs will be considered by the relevant IFR Panel including those considered via the fast-track procedure.

IFRs for drugs will be considered by the IFR drug panel, IFRs for other interventions will be considered by the IFR intervention panel.

Both panels are subcommittees of the Planned Care Programme Board.

The Chair is responsible for the conduct of the meeting, determining whether the meeting is quorate, and ensuring that the Agenda is completed.

Panel meetings will be held in private. Requesting clinicians or patients will not be invited to make representations in person. The Panel may ask specialists to attend the meeting and advise members during their deliberations.

During the meeting the Panel members will consider:

- new submissions
- submissions deferred from an earlier meeting pending the availability of evidence/information
- follow-up information relating to earlier conditional approvals
- ratification of decisions made using the fast-track procedure

The Panel will also note submissions that have been withdrawn and in respect of which no action or decision is required.

In the second part of the IFR Panel Meeting (Part 2) the IFR Panel will consider new submissions for which a service development is required but which requires early consideration due to a clear clinical reason having been identified which would

significantly compromise the patient's health if the patient had to wait until a service development decision was made.

Submissions for Drugs IFRs
The IFR drug panel meets bi-weekly (see Appendix 4 for TOR). Dates will be set quarterly in advance.

Submissions for Interventions IFRs
The IFR intervention panel meets bi-weekly, but the frequency may be subject to variation over time. Dates will be set quarterly in advance. (See Appendix 4a for TOR)

2.10 Principles to be applied by the IFR Panels

Each IFR will be considered on its own merits. Decisions will be taken using the agreed Consensus Decision-making Process (see Appendix 5) and IFR panel members will have received training on this as part of their induction training.

The SEC Ethical Framework (see Appendix 6) will be used to support the decision-making process and will help to promote consistency across the SEC Strategic Health Authority (SHA). In keeping with the principles of the SEC Ethical Framework, the IFR panels will need to take an objective view of the submission, and maintain an open mind about the information and factors to be considered.

The IFR panels shall be entitled to approve requests for funding for treatment for a named patient where all four of the following conditions are met:

- Either (a) a rarity request for funding for treatment in connection with a presenting medical condition for which the PCT has no policy or (b) an exceptionality request for funding for treatment in connection with a medical condition for which the PCT has a policy and where the patient has demonstrated exceptional clinical circumstances;
- There is sufficient evidence to show that, for the named patient, the proposed treatment is likely to be clinically effective;
- Applying the approach that the PCT takes to the assessments of costs for other treatments outside this policy, the cost to the PCT of providing funding to support the requested treatment is justified in the light of the benefits likely to be delivered for the named patient by the requested treatment.
- The request for this patient is not a request for a service development (and therefore not one to be considered in part 2 of the meeting).

The IFR panel shall determine, based upon the evidence provided to the panel, whether the patient has demonstrated exceptional clinical circumstances.

Whether a patient can demonstrate "exceptional clinical circumstances" will depend on the precise and particular clinical facts of the individual case and whether those can genuinely be described as exceptional.

For instance evidence which is identified as showing that, for the individual patient, the proposed treatment is likely to be clinically effective may be part of the case put

by the requesting clinician to say that the patient's clinical circumstances are exceptional. However in order to determine whether a patient is able to demonstrate exceptional clinical circumstances the IFR panel shall compare the patient to other patients with the same presenting medical condition at the same stage of progression.

When considering exceptionality the IFR panels (drug and intervention) will consider that a named patient who has clinical circumstances which, taken as a whole, are outside the range of clinical circumstances presented by at least 95% of patients with the same medical condition at the same stage of progression as the named patient could show that their clinical circumstances were sufficiently unusual that they could properly be described as being exceptional. Whether or not a named patient demonstrates "exceptional clinical circumstances" however is a matter for determination by the IFR panel dependent on the precise and particular clinical facts of the individual case.

The IFR panel should take care to avoid adopting "the rule of rescue" approach. The fact that a patient has exhausted all NHS treatment options available for a particular condition is unlikely, of itself, to be sufficient to demonstrate exceptional circumstances. Equally, the fact that the patient is refractory to existing treatments where a recognised proportion of patients with the same presenting medical condition at the same stage are, to a greater or lesser extent, refractory to existing treatments is unlikely, of itself, to be sufficient to demonstrate exceptional circumstances.

2.11 Decisions Available to the Panel

When considering a new submission, the panel may decide as follows:

- the request will be **funded without conditions**
- the request will be **funded with conditions** attached
- the request will **not** be **funded**
- the submission cannot be decided at this meeting because more evidence/information is required and is therefore **deferred**

2.12 Deferred Submissions

IFR Panels may decide to defer a decision because information called for before the meeting is not yet available, or because the panel members decide at the meeting that they need more information. If a decision is deferred the Chair of the panel must make a decision on whether the deferred IFR should be fast-tracked (see section 2.7) or whether the deferred decision can be re-considered at the next panel providing the information is available.

The status and progress of deferred submissions must be reviewed within one month of the decision to defer. If the required information is still not available the panel may decide to defer for a second time.

The minutes of the meeting at which the second deferral is made must record in detail the reasons why a decision cannot be made (for example, information has been requested from a specialist in a very rare disease who is located outside the UK, and a response has not yet been received). The IFR panel may ask for alternative sources of information to be used.

All submissions must be considered and a decision made in respect of each within two months of the date of the first decision to defer. The aim is to ensure that submissions which have been deferred, and for which information is not forthcoming, are not allowed to languish without a decision for an unacceptable period of time.

Once the IFR panel is in a position to make a decision, it may decide:

- the request will be funded without conditions
- the request will be **funded with conditions** attached
- the request will **not** be **funded**

2.13 Conditional Approval

IFRs may be approved for funding subject to conditions.

In some cases the IFR panel will need to be advised of the patient's status at an interim point in order to approve a second phase of treatment. For example, a requesting clinician may request 6 cycles of a treatment but advise that a response may be observed within 3 cycles. The IFR panel may agree to fund 3 cycles, but decide that funding for a further 3 cycles will be conditional upon the patient's response and the submission to the panel of a report detailing the response observed after the first 3 cycles will be required for further consideration to be given to the submission.

2.14 IFRs can be withdrawn

IFRs can be withdrawn at any time by written notice / email from the requesting clinician and /or from the patient. The IFR panel will note that a submission has been withdrawn at the next available meeting.

For example, it may be necessary to withdraw if the patient opts for an alternative course of treatment, or opts to fund treatment privately, or has in the interim passed away.

2.15 Record of Panel Meetings and Confidentiality

All discussion during a meeting of the IFR panel will be confidential.

At the end of the meeting all the copies of the papers from panel members will be collected. One complete set of original records will be retained electronically on the high cost drugs database or treatment not routinely funded database as appropriate.

Members of the fast-track group will be instructed to forward relevant emails and faxes, and then to destroy their own copies. All details are entered onto the patient's records on the high cost drugs database or treatments not routinely funded database as appropriate.

The panel's decision, including the rationale for the decision will be clearly recorded in the minutes which will be signed off in paper form by the chair of the Panel Meeting and filed for record keeping.

The wording used to convey the panel's decisions, conditions and rationales in the minutes will be transcribed **exactly** into the decision letters which will be signed of by the Chair of the Panel meeting before being sent. Any error or ambiguity in this wording is the responsibility of the Chair.

When preparing minutes, both the Secretary/Administrator and the Chair should bear in mind that these are documents which could be discloseable and use language accordingly. The decisions of an IFR panel are attributable to the panel as a whole. The minuting of discussion about specific concerns raised by individual submissions should avoid personalities.

The items of general business in the minutes should include:

- The date, time and place the meeting was held
- The name of all members present, including a note of any member arriving late or leaving early and the items for which they were present
- The name of the Chair
- The name of any member submitting apologies for non-attendance
- The name of any observer / expert adviser who attended and the items for which they were present

For each individual submission considered by the panel the minutes should record:

- The unique reference number of the submission
- The status of the submission (i.e. new submission, second consideration of deferred submission, ratification of sub-committee decision, interim report on patient condition following conditional approval)
- The name of any member who declared an interest in or association with the submission, and the nature of the declaration (the chair to determine whether they should leave the meeting during discussion of that item)
- All the items of information considered with regard to the submission
- Note of the written comments on the submission made by any IFR panel member not present
- A summary of the opinion given by any special advisors attending the meeting
- Specific concerns raised by this submission and the panel's response to them
- The decision reached and the degree of consensus (shown as X out of Y, where Y is the maximum, depending on the number of panel members)
- Any conditions attaching to the decision (exact wording to be advised by the chair) including if and when a follow-up report is required
- The rationale for the decision (exact wording to be advised by the chair)

- The form of words to be used in communicating a negative decision and rationale to the patient (exact wording to be advised by Chair)
- Further information required and/or actions in the case of a deferred decision

Copies of the minutes will not be distributed to panel members for their retention and will not be placed in the public domain. This is in the interests of preserving patient confidentiality. Although patients' names have been removed, the IFR process is by definition dealing with rare conditions. The singularity of these may be enough to identify an individual.

Submissions for Drug IFRs

Notes of an IFR drug panel meeting will be taken by a member of the Pharmaceutical Commissioning team and will be written up as formal minutes within 24 hours and approved by the Chair within 2 working days of the meeting.

Submissions for Intervention IFRs

Notes of an Interventions IFR panel meeting will be taken by the TNRF Panel Administrator and will be written up as formal minutes within 72 hours and approved by the Chair within 5 working days of the meeting.

2.16 Communicating the Panel's Decision

Submissions for Drugs IFRs

The IFR panel's decision will be communicated by email to the individual or requesting clinician who submitted the IFR. The letters communicating the decision are signed by or on behalf of the Chair.

Within 3 working days of the IFR drug panel meeting the Pharmaceutical Commissioning team will:

- E-mail the individual or requesting clinician who submitted the IFR to convey the panel's decision, any conditions attached to funding agreed and whether the conditions require any interim report on the patient's status
- Write to the patient (or his/her representative) to convey the panel's decision, provided the patient has indicated they wish to receive such communication using appropriate language. A copy of the letter will be sent to the requesting clinician to enable him / her to discuss this with the patient at their next clinic appointment.
- Update the High Cost Drugs Database
- Produce a summary report for Planned care Programme Board / Risk & Clinical Governance and Commissioning Executive which is collated on a quarterly basis

Submissions for Interventions IFRs

The IFR panel's decision will be communicated by letter to the individual or requesting clinician who submitted the IFR. The letter communicating the decision will be signed by or on behalf of the Panel Chair.

Within 10 working days of the IFR intervention panel meeting the Acute Contracting TNRF team will:

- Write to the requesting clinician to convey the panel's decision, any conditions attached to funding agreed, and whether the conditions require any interim report on the patient's status.
- Copy the letter to the patient (or his/her representative) to convey the panel's decision, provided the patient has indicated they wish to receive such communication, using appropriate language.
- Update the TNRF Database
- Produce summary report for Planned care Programme Board / Risk & Clinical Governance and Commissioning Executive which is collated on a quarterly basis

2.17 Time Periods for IFR Process

Submissions for Drugs IFRs

NHS Surrey will work to the standard that funding decisions will be provided within 18 working days. Achievement of this standard is dependent upon the PCT receiving complete requests together with the relevant references to support the submission. This standard applies from the point at which NHS Surrey receives full information from the requesting clinician.

Submissions for Intervention IFRs

NHS Surrey will work to the standard that funding decisions will be provided within 28 working days. Achievement of this standard is dependent upon the PCT receiving complete requests together with the relevant references to support the submission. This standard applies from the point at which NHS Surrey receives full information from the requesting clinician.

3 THE IFR APPEAL PROCESS

The IFR Appeal process enables patients and their clinicians to appeal against a decision made by an IFR panel. The Appeal process is independent of the IFR process.

An IFR Appeal panel will not consider new evidence. If new evidence becomes available after a decision not to fund has been made by an IFR panel, then the correct procedure is for the requesting clinician to submit a new IFR submission form supported by the new evidence, not to appeal the existing decision.

The numbers of appeals that may be received are difficult to predict and therefore arrangements for Appeal panel meetings are to be flexible and will be made in response to demand. The Appeal panel will aim to meet within 20 working days of an Appeal being received by NHS Surrey but this may not always be possible.

3.1 Grounds for Appeal

The decision of an IFR panel can be appealed on the grounds of:

- That there was procedural irregularity in the original decision making process
- There is evidence to suggest that the IFR Panel failed to consider and take into account relevant information, or apply appropriate weighting to that information when reaching its decision.

3.2 Remit of the IFR Appeal Panel

The IFR Appeal panel will review all the documents relating to the appeal, the original IFR submission and the IFR panel's decision. The Appeal panel will consider whether they are satisfied that:

- The IFR panel acted in accordance with the PCT's approved procedures
- The decision was consistent with the SEC Ethical Framework for decision-making and the principles set out in the Policy and Operating Procedures for dealing with IFRs
- The IFR panel properly considered the scope and nature of evidence
- In reaching its decision the IFR panel took into account and weighed all relevant factors.

If the IFR Appeal Panel concludes following such a review that the decision cannot be supported on any one of the above grounds, the case must be sent back for re-consideration by the relevant IFR panel.

3.3 Lodging an Appeal

The appeal should be lodged within one calendar month of the date of the letter to the requesting clinician and/or patient notifying them of the decision of the IFR panel. The appeal can be lodged by:

- The requesting clinician who submitted the original IFR
- The patient
- The legal guardian where the patient is a child under 18 years of age
- A person appointed with lasting power of attorney if the patient lacks the mental capacity to lodge an appeal themselves
- A third party (e.g. friend or relative) with the documented consent of the patient

If the requesting clinician lodges the appeal s/he is required to confirm that s/he has discussed the appeal process fully with the patient and is acting with his/her consent. If the patient or his/her representative lodges the appeal the representative should have the support of the clinician who originally requested the IFR.
The person lodging the appeal should write to NHS Surrey stating that they wish to appeal and the grounds on which the appeal is being made, confirming that they have the consent of the patient.

The appeal will be acknowledged in writing to the requesting clinician and/ or the patient or his/her representative within three (3) working days of receipt of the appeal. Appellants will then have 20 working days in which to provide as much information/ evidence as possible in support of their appeal.

3.4 Information Provided by the Clinician or Patient

The Appeal Panel will meet in private and the patient or his/her clinician will not be invited to attend.
The appellant will have been given the opportunity to make written representation and/or provide such literature and material as they consider appropriate in support of the Appeal. This may be provided by the clinician and/or the patient and on behalf of the patient by guardians, representatives, family members, carers etc.
Information provided by the clinician should be in English and in writing or a conventional clinical medium such as x-ray or scan results provided these are accompanied by a report with interpretation from the appropriate specialist and/or consultant.

3.5 Actions in Advance of the Meeting

As soon as the date of the Appeal panel meeting is confirmed the appellant will be informed of that date.
Appeal Panel members will receive the Agenda and papers in support of an Appeal no less than 3 working days before the meeting. For each appeal the members will receive copies of:

- All papers considered by the original IFR panel, including the original submission form, supplementary information and evidence review
- The minutes of the IFR meeting(s) at which the submission was considered and decided
- A written statement summarising any advice given verbally by specialists attending the meeting
- The decision letter

- The letter lodging the appeal
- The further information provided by the patient, his/her representative, and the clinician in support of the appeal.

If a Panel member requests further information or raises a question about the panel papers, both the request/question and the response will be circulated to all members as soon as possible. The Appeal panel may, in appropriate cases, seek external advice.

3.6 Appeal Panel Meeting and Decision

All discussion during the Appeal panel meeting will be confidential. Decisions will be taken using the Consensus Decision-Making Process (Appendix 5). The SEC Ethical Framework for decision making (Appendix 6) will be applied throughout the Appeal process.
The Appeal panel may uphold or overturn the decision of the original IFR panel. Reasons for the Appeal panel decision must be clear. A decision to overturn does not mean that the request will be funded: it means that the request will be considered again by the appropriate IFR panel. The Appeal panel may not defer the making if a decision.

3.7 Minutes

Notes of an Appeal panel meeting will be taken and written up as formal minutes within 24 hours. The minutes will record:

- The decision taken
- The reasons for the panel's decision
- The consensus reached

The minutes will be written up and verified and approved by the Chair within five (5) working days of the meeting. The text of the minutes will be used in communicating the panel's decision to the appellant. Copies of the minutes will not be distributed to panel members for their retention and will not be placed in the public domain. This is in the interests of preserving patient confidentiality.

3.8 Communicating the Decision

The decision of the Appeal panel will be notified in writing and sent by secure means to the appellant within ten (10) working days of the meeting.

3.9 Next Steps

If the Appeal panel upholds the original IFR panel's decision, the appellant will be advised that if they wish to take the matter further this must be done through the NHS Complaints process.
If the Appeal panel overturn the original IFR panel's decision the appellant will be advised that the original IFR submission will be reconsidered by the next available IFR panel, with that Panel taking account of any additional evidence which has

become available in the interim. NHS Surrey will ensure the IFR submission is reconsidered at the earliest possible opportunity.
If the IFR panel who reconsider the submission upholds the original IFR panel's decision, the appellant will be advised that if they wish to take the matter further this must be done through the NHS Complaints process.

4 APPROVAL, RATIFICATION AND REVIEW PROCESS

This policy will be subject to review after one year and at any stage at the request of either management or the joint negotiating and consultative committee or a change in legislation or national guidance.

5 DISSEMINATION AND IMPLEMENTATION

Dissemination of this document will be organised centrally in accordance with the 'Organisation–wide Policy for the Development and Management of Procedural Documents' and disseminated and implemented as follows:

- A copy of the policy will be held on the Portal
- Copies will be made available on NHS Surrey's website and Surrey Community Health's extranet
- Directors will convey the contents of the policy to their department managers
- Managers will convey the contents of the policy to members of staff and ensure they have read and understood the document and abide by its contents
- The policy will be shared with all relevant stakeholders.
- This policy will be brought to the attention of all staff and monitored in line with normal assurance processes.

6 GLOSSARY

- SEC: South East Coast
- SEC SHA: South East Coast SHA
- IFR(s): Individual Funding Request(s)
- HPSU: Health Policy Support Unit
- MPOP: Model Policy and Operating Procedures
- TNRF: Treatments Not Routinely Funded
- PCT: Primary Care Trust, this is used interchangeably with NHS Surrey throughout the document

APPENDIX 1 – Individual Funding Request Form

Please read the guidance notes on the back page before completing this form

PART 1: DETAILS OF PATIENT AND CLINICIAN SUBMITTING REQUEST

1 Details of clinician submitting the request	Name:	
	Designation:	
	NHS Trust or GP practice:	
	Correspondence address:	
	Tel:	
	Email:	

2 Patient details	Family name:			
	Given names:			
	Address (including Postcode):			
	NHS Number:			
	Date of Birth:		M or F	
	Registered GP name:			
	Registered GP practice:			
	Hospital id no: (if applicable)			

3 Instructions for communicating with the patient	Does the patient or his/her representative wish to receive letters regarding this request? ☐ yes ☐ no
	If YES are the letters to be sent to the patient at the address above? ☐ yes ☐ no
	If letters are to be sent to anyone other than the patient, please provide the following information, and obtain the patient's written agreement:
	Name
	Relationship to patient
	Address (including Postcode)

PART 2: INFORMED CONSENT AND PROVIDER TRUST APPROVAL

4 Clinician's affirmation of patient's consent	I affirm that I have discussed this Individual Funding Request with my patient. This request is being made with his/her consent. The instructions for communicating with the patient at Q3 are his/her expressed wishes.	
	Signature	
	Name:	
	Designation:	

5 Which organisation will be providing the treatment requested?	□ NHS Trust □ GP/dental practice □ Private sector □ Other	
	Name of NHS Trust/GP/dental practice:	
	If provider is outside the NHS, please give details of name and location	

6 Approved by representative of NHS Trust/GP practice where the treatment will be provided	Name of representative:	
	Designation:	
	Signature or email confirmation:	
	If this funding request is approved, the NHS provider will be notified. Please give details for the person who should be notified:	
	Name:	
	Designation:	
	Contact details:	

NHS Surrey use only:

Date received:	
Identifier:	
Identifier assignment checked by:	

Please note, pages 1 and 2 containing confidential details of patient's name, etc. will be removed before the remainder of the form is copied and seen by IFR panel members.

PART 3: STATEMENT TO CONFIRM APPROPRIATENESS FOR CONSIDERATION BY IFR PANEL

If it is foreseeable that there are one or more other patients within the PCT population who are or are likely to be in the same or similar clinical circumstances as the requesting patient in the same financial year, and who could reasonably be expected to benefit to the same or a similar degree from the requested treatment then the request should properly be considered as a request for a service development and inappropriate for consideration by an IFR Panel except in the circumstances where all the similar patients are expected to be from the same family group, a situation which may arise in the context of a rare genetic disease.	
I confirm that it is not expected that there will be more than one patient from within the PCT population who is or is likely to be in the same or similar clinical circumstances as the requesting patient in the same financial year and who could reasonably be expected to benefit to the same or a similar degree from the requested treatment unless similar patients are expected to be from the same family group.	□ NO □ YES

PART 4: DIAGNOSIS AND PATIENT'S CURRENT CONDITION

7 Diagnosis (for which the intervention is requested)		
8 Has a second consultant opinion been obtained?	***If YES, please give details***	
9 Current status of the patient: (a) Intervention for **cancer:**	What is disease status? (e.g. at presentation,1st,2nd or 3rd relapse)	
	What is the WHO performance status?	
	How advanced is the cancer? (stage)	
	Describe any metastases:	
(b) Intervention for **non-cancer**	What is the patient's clinical severity? (Where possible use standard scoring systems e.g. WHO, PASI, DAS scores, walk test, cardiac index etc.)	
10 Please summarise the current status of the patient in terms of quality of life, symptoms etc.		

11 Summary of previous interventions for this condition *Reasons for stopping may include:* • course completed • no or poor response • disease progression • adverse effects / poorly tolerated	Dates	Nature of intervention	Reason for stopping*/ response achieved

PART 5: INTERVENTION FOR WHICH FUNDING IS REQUESTED

12 Nature of the intervention *If combination, tick all that apply and complete 6A and 6B*	☐ Drug ☐ Surgical procedure ☐ Medical device ☐ Therapy ☐ Other (*give details*)
13 Name of intervention	
14 Where will intervention be provided?	*Indicate whether in-patient, out-patient, daycase*
15 Is the requested intervention a continuation of existing treatment funded via another route?	☐ NO ☐ YES *- give details of existing funding arrangement and why ceased*
16 Is the intervention experimental, part of a trial or research?	☐ NO ☐ YES *- give details*

PART 6A: INTERVENTIONS INVOLVING DRUGS

17 Full name of drug and manufacturer		
18 Planned dose and frequency		
19 Planned duration of intervention		
20 Route of administration		
21 Optimal start date		
22 If the intervention forms part of a regimen, please document in full	*(e.g. Drug X as part of regimen Y (consisting of drug V, drug W, drug X and drug Z).*	
23 Drug licensed for requested indication in the UK?	☐ YES ☐ NO	
24 Drug listed as a PBR exclusion?	☐ YES ☐ NO	
25 Estimated costs *Please consult Pharmacy team for current contract prices as these may differ from those stated in BNF or other sources.*	Anticipated cost (inc VAT)	
	Are there any offset costs?	☐ YES ☐ NO
	Describe the type and value of offset costs	
	Funding difference being applied for	

PART 6B: INTERVENTIONS INVOLVING SURGICAL PROCEDURES, THERAPIES, DEVICES

26 Describe the intervention as it applies to this patient		
27 Is this intervention listed by the PCT as a Procedure Not Normally Funded	□ YES □ NO	
28 Specify any devices, prostheses, etc. and the manufacturer		
29 Estimated costs *Please consult the relevant business manager for assistance*	Anticipated cost (inc VAT)	
	Are there any offset costs?	□ YES □ NO
	Describe the type and value of offset costs	
	Funding difference being applied for	

PART 7: PROJECTED OUTCOMES

30 Is there a standard intervention for this patient at this stage of their condition?	*If so, please describe the standard intervention*
31 What would be the expected outcome from the standard intervention?	
32 Why is the standard intervention inappropriate for this patient?	
33 What would you consider to be a successful outcome for the requested intervention in this patient?	*This may include likely OS, TTP or improvement in QOL. Please relate to measures describing patient's condition in Part 3.*
34 Please outline any anticipated or likely adverse effects of the requested treatment for this patient, including the toxicity of any drug?	

PART 7 CONT.

35 How would you monitor the effectiveness of the requested intervention?	*Pease refer to the measures used to describe the patient's condition in Part 3*
36 What is the minimum timeframe/course of treatment after which a clinical response can be assessed?	
37 What are the likely consequences for the patient if this request is not approved?	

PART 8: STATEMENT OF EXCEPTIONALITY OR RARITY

38 On which basis are you making this request?	☐ Exceptional clinical circumstances **OR** ☐ Rarity of condition or presentation
39 For exception to existing policy, please describe as clearly as possible why the patient's clinical circumstances are exceptional. *You must give **specific** information to indicate how this patient is significantly different to the population considered in the existing policy*	
40 For rare condition or presentation, please describe as clearly as possible why this patient's condition or clinical presentation is so unusual that there is no relevant commissioning arrangement.	

PART 9: EVIDENCE OF CLINICAL EFFECTIVENESS

41 Give details of published data supporting the use of the requested intervention for this condition. *Please provide references or attach articles.*

PART 10: URGENCY

42 Only a small minority of requests can be decided using the PCT's fast-track procedure. If there are compelling clinical reasons why this patient's request should be fast-tracked, please state them here.	

Thank you for completing this form; please send it to:

For drug IFR requests please send as an electronic attachment to:
highcost.drugs@nhs.net
(From 1st April 2010 please send via web-based database
https:\\www.healthlinx.co.uk\highcost-trust)
For intervention IFR requests please send as an electronic attachment to tnrf@nhs.net
or post to:
Acute Contracting (TNRF) Team, NHS Surrey
Pascal Place, Randalls Research Park
Randalls Way
Leatherhead
Surrey. KT22 7TW
Or Safe Haven Fax: 01372 202690

GUIDANCE NOTES FOR CLINICIANS COMPLETING THIS IFR FORM

IFR Policy and further information

SEC PCTs have adopted a SEC-wide approach to the management of IFRs. Before submitting an IFR, please check you are using the correct process. IFRs can be submitted by an NHS consultant, a GP or dental practitioner, or an equivalent autonomous practitioner where he/she will be responsible for administering the treatment. The requesting clinician is responsible for providing all supporting information and evidence.

If treatment is to be provided at an NHS Trust, the IFR must be approved, and this form signed, by the appropriate representative of that NHS organisation. This will usually be the chief pharmacist or a business manager (or their nominated deputy). This approval ensures that capacity issues have been considered.

Uncertain? We WANT to help you!

NHS Surrey has divided the way that IFRs are processed. All drug related IFRs are handled by the Pharmaceutical Commissioning Team and considered by the IFR drug panel, all other interventions are handled by the Treatments not Routinely Funded team and considered by the IFR intervention panel. Both teams would much rather answer your questions than send the form back to you because it is not properly completed. If you would like help to complete this form, please don't hesitate to contact us via email.

Why all these questions?

Please be assured there is good reason for *all* the questions on this form. Not every question need be answered for every case; but please signify 'not applicable' rather than leaving a blank.

Part 1: Details of patient and clinician submitting the request

We need to contact you – so full details *every* time please. We must be able to identify the patient. Please ask your patient to choose whether s/he wishes to receive correspondence about the progress of his/her IFR: if YES please indicate where letters should be directed.

Part 2: Informed consent and provider approval

Your signature at this point validates the whole request. Details of the provider (and approval, where appropriate) are essential. An unsigned form cannot be accepted.

Part 3: Statement to confirm appropriateness for consideration by IFR panel

Affirmation of the statement confirms that, to the best of your knowledge, the request is an appropriate IFR. Where you are unable to confirm the statement, your request for funding will need to be considered via another mechanism.

Part 4: Diagnosis and the patient's condition

The fullest possible information will help the panel make a decision. Q8 will not be relevant to every case. At Q9 complete *either* (a) or (b). Q11 may not be relevant to every case.

Part 5: Intervention for which funding is requested

Please name the intervention clearly, and describe the detail if necessary. If the answer to either Q15 or Q16 is YES, please provide the details separately if the space on the form is insufficient.

Part 6A: Interventions involving drugs / Part 6B: Interventions involving surgical procedures, etc.
In most cases it will only be necessary to complete *either* A or B. It is likely that this information will be required before the NHS provider can approve the form. Information on likely costs helps the PCT to be aware of potential cost pressures.

Part 7: Projected outcomes
Again, the fullest possible information will help the panel come to their decision.

Part 8: Statement of exceptionality or rarity
At Q38 you must choose *either* exception or rarity - otherwise the form will be returned. At Q39 please state as clearly as possible, and with reference to the existing policy, why your patient should be treated as an exception; OR at Q40 provide clear information about the rarity of your patient's condition or presentation.

Part 9: Evidence of clinical effectiveness
Comprehensive information and accurate references will help to get your IFR through the process quickly.

Part 10: Urgency
We aim to deal with all IFRs as quickly as possible. Each IFR can only be decided when sufficient information is available to inform the decision. Urgency will be evaluated on the basis of clinical need.

For help in filling this form out in relation to drug IFRs please email your query to the Pharmaceutical Commissioning Team at highcost.drugs@nhs.net who will be able to help you.

For help in filling this form out in relation to other intervention IFRs please email your query to the TNRF Team at tnrf@nhs.net

APPENDIX 2 – Individual Funding Request (IFR) Intervention Triage Meeting Terms of Reference

1.0 PURPOSE / REMIT

On receipt of an intervention IFR the Acute Contracting TNRF team will check for completeness before the intervention triage meeting to ensure:

- The PCT is the Responsible Commissioner for that patient
- All contact details have been provided
- The appropriate form has been submitted and all parts of the form are fully completed
- All supplementary documentation referred to is attached
- The submission has been approved by a suitable representative of the Trust providing treatment (as appropriate)

Providing the intervention IFR fulfils the above the IFR will then be submitted to the next IFR Intervention Triage Meeting. The purpose of the IFR Intervention Triage Meeting is to assess all intervention IFR submissions for their eligibility for consideration by the IFR Intervention Panel, in accordance with the NHS Surrey Policy and Operating Procedures for dealing with IFRs.

The purpose of the IFR Intervention Triage Meeting is therefore to determine eligible and ineligible submissions to the IFR Intervention Panel and to consider whether the treatment requested:

- Is funded within existing commissioning policy?
- Is covered by another PCT policy or process?
- Amounts to service development and thus requires a PCT policy decision?

The IFR Intervention Triage Team will ensure that submissions that do not go forward to the IFR Interventions Panel are sign-posted to the most appropriate route, in accordance with the NHS Surrey Policy and Operating Procedures for dealing with IFRs.

The IFR Intervention Triage Team will then assess each individual submission against the definitions of **a "rarity request"** or an **"exceptionality request"** as set out in the NHS Surrey Policy and Operating Procedures for dealing with IFRs.

Eligible Intervention IFRs will be forwarded for consideration at the next IFR Intervention Panel, providing sufficient information is available, in accordance with the NHS Surrey Policy and Operating Procedures for dealing with IFRs.

2.0 ACCOUNTABILITY

The IFR Intervention Triage Team is accountable to the IFR Intervention Panel, and to the Planned Care Programme Board.

3.0 MEMBERSHIP

The IFR Intervention Triage Team shall comprise:

- IFR Public Health Clinical Lead
- Acute Contracts IFR Lead
- IFR Administrator

The Team reserves the right to request the ad hoc attendance of any other member of staff as it requires.

4.0 QUORUM

The Meeting will be considered quorate if the IFR Public Health Clinical Lead and the Acute Contracts IFR Lead are present.

5.0 FREQUENCY

The Team shall meet bi-weekly, unless no submissions are received, in which case the meeting shall be cancelled.

6.0 REPORTING

The minutes of the meetings shall be recorded.

The IFR Intervention Team will maintain a record of ineligible submissions, noting the reasons why considered ineligible, in accordance with the NHS Surrey Policy and Operating Procedures for dealing with IFRs.

7.0 REVIEW

The terms of reference of the IFR Intervention Triage Meeting shall be reviewed by the Planned Care Board at least annually.

APPENDIX 3 – Standard Operating Procedure for Processing Drug IFRs

Background:

IFRs for drugs are submitted to NHS Surrey by its providers (e.g. local Acute Trusts and Tertiary centres). IFRs for drugs are processed by the pharmaceutical commissioning team and presented to the IFR drug panel (fortnightly) who make a decision on funding of the requested intervention.
Complete enquiry documentation is an audit standard and allows collation of correct statistical information relating to the handling of IFR drug requests.

Objective/ aim of procedure

To ensure full and complete documentation is achieved for all drug IFRs processed by the pharmaceutical commissioning team at NHS Surrey.

Risk Management Notes

Clear and comprehensive documentation is necessary for legal and ethical reasons, in order to ascertain exactly what information was provided, by whom and what resources were used.

This also ensures that an enquiry can be located at a later date, to save time in dealing with future enquiries.

Procedure

1. All drug IFRs for NHS Surrey should be submitted as an electronic attachment to highcost.drugs@nhs.net. It is the responsibility of the pharmaceutical commissioning team to check the account daily as per the highcost.drugs@nhs.net standard operating procedure (from the 1st April 2010 all submissions must be sent electronically via the web-based database https:\\www.healthlinx.co.uk\hicost-trust)

2. Where drug IFR submission forms are hand written, these must be sent back to the requesting Trust with a request that it resubmits the form as an electronic attachment to the pharmaceutical commissioning team email account (or the web-based database from 1st April 2010).

3. When a drug IFR is received the submission is to be checked to ensure that the patient is registered with a Surrey GP. A list of GPs can be accessed via Y drive/Public Health/Prescribing/High cost & NICE drugs/ adhoc information/Practice and GP postcodes or access to NSTS is available to the pharmaceutical commissioning team. A smart card is required to view the system and all full time members of the team will be given access to this system. This system shows the patient's GP and the PCT responsible for the patient.

4. The submission form must then be checked for completeness and that it has been approved by a suitable representative of the Trust. The requesting Trust should be contacted for clarification where any information is missing.

5. A decision about appropriateness for consideration by the IFR drugs panel must then be made (see section 2.4 of policy):

   - is the request funded within the existing commissioning policy
   - is the request covered by another PCT policy or process
   - does the request amount to a service development thus requiring PCT policy

6. Before processing a IFR check "Question 42" on the IFR Request Form to see if a decision is required urgently. Where a case has been identified as urgent the processor needs to confirm this with the requesting Trust and then follow the process set out in the fast-tracking urgent IFRs section of NHS Surrey Policy and Operating Procedures for dealing with IFRs (section 2.7).

7. It is the responsibility of the processor to email the Trust and acknowledge receipt of the IFR Form and to inform them of the next available panel date (unless otherwise agreed with another member of the pharmaceutical commissioning team)

8. Check on NHS Surrey's High Cost Drugs database https://www.healthlinx.co.uk/hicost to see if a previous funding submission has been received for the same patient.

9. The processor must then ensure that the drug IFR request is saved onto NHS Surrey's High Cost Drugs database following the relevant procedure (see database SOP). NB: The request must be saved as a submission and then again as a PCT version without the first 2 patient identifiable pages. This ensures that any questions raised in the future regarding the original submission can be answered. At this point a unique identifier will be assigned to the submission. The first section of the from (parts 1 and 2) containing the identity of the patient and clinician will be separated. From this point forward the submission form will be anonymised and distinguished only by the identifier.

10. Ensure that all information from the Trust or parties related to the funding submission (letters, pictures etc) are anonymised and scanned onto NHS Surrey's High Cost Drugs database.

11. Process the PCT version of the form as follows: select all text and change to Arial, font size 10 and ensure the document is set to single spacing (under format, paragraph). Ensure there are no gaps within the document and choose the double sided option when printing the document. Ensure

that blank pages and contact details of PCTs at the bottom of the form are deleted (not relevant for panel discussion)

12. The processor should ensure that all relevant information is included. If there are any gaps or whilst reading the form the processor has questions or knows what the members of the panel will ask, contact the requesting clinician to seek clarification.

13. When editing the form ensure that the words 'PCT comments' are annotated into the relevant boxes (so that it is clear which information was from the Trust and which came from the PCT)

14. Check the wording of the license on summary of product characteristics (SPC) (http://emc.medicines.org.uk/).

15. Published data section (question 41): This section is where the evidence for the intervention is reviewed. The following headings/information should be provided:

    - **Trust Identified Information** for all information submitted by the Trust. Where links to a journal have been provided these should be replaced with the journal, title, author and dates. Where the full document can be obtained a critical appraisal of the paper must be done by the processor. If the full paper cannot be found then the Trust should be contacted and asked whether they can forward this on. Alternatively contact Guys and St Thomas's Medicines Information department as they can sometimes send the full paper or critically appraise the paper. Where it is not possible to get access to the whole paper from the Trust or Guys and St Thomas's Hospital then the abstract must be included. Any comments from the Trust about the evidence they have submitted will be preceded with the words '**Trust Comment**' so that there is no misunderstanding where the comments have come from.

    - **PCT Identified Information** for all information identified by the processor whilst conducting a search or review.

    The processor must ensure that clinical trials are summarised and a PCT comment made which makes reference to the relevance of the particular trial/information to the particular patient. Also make reference in the PCT comment to the trial and its robustness.

16. Document the search in the order the resources have been searched. A list of search terms used must be documented and the date the resources were accessed. Where nothing has been found, "Nil found" should be recorded. A standard search should include:

    - NHS Evidence (www.evidence.nhs.uk). Developed by NICE and incorporates some of the key components from the former National Library for Health (NLH).

- The National Electronic Library for Medicine (www.nelm.nhs.uk) including a reference to whether a review has been carried out by the LNDG / LCNDG
- Embase (via www.library.nhs.uk).
- SPC (via www.medicines.org.uk)
- Contact the manufacturer of the requested drug for any other relevant trial information (see below)
- Medline may also be used (has American focus) via www.library.nhs.uk
- NICE guidance – www.nice.org.uk
- SIGN guidance – www.sign.ac.uk
- SMC – www.scottishmedicines.org.uk
- AWMSG (All Wales Medicines Strategy Group) – www.wales.nhs.uk
- New Product Evaluation – saved on Y drive (Public Health /Prescribing/High cost & NICE drugs/ Horizon scanning)
- South East Coast Health Policy Support Unit - http://nww.sechealthpolicysupportunit.nhs.uk/prs-and-reports/
- Relevant Professional Bodies e.g.:
  - British Society of Rheumatology www.rheumatology.org.uk
  - British Association of Dermatology www.bad.org.uk
  - Royal College of Ophthalmologists www.rcophth.ac.uk
  - American Society of Haematology http://bloodjournal.hematologylibrary.org/misc/ASH_Meeting_Abstracts_Info.dtl
  - British Society of Haematology www.bcshguidelines.com

For rare cancer enquiries, also search the American Society of Clinical Oncologists (www.asco.org), clinicaltrials.gov and US National Comprehensive cancer network (www.nccn.org). It may also be relevant to contact drug companies Medical Information department especially when published information is lacking.

17. The processor must also ensure that prevalence data is incorporated in the request. The following websites can be used but it might also be useful to contact the requesting clinician for prevalence data if in doubt. The Cancer Research UK website www.cancerreasearchuk.org and the National Statistics website www.statistics.gov.uk are useful tools for this purpose.

18. Clearly state the names of all resources used, with additional information as follows:

- Books: specify edition number and page number(s).
- Journals: specify year, volume and page number(s).
- Databases: specify dates searched/accessed and state search terms used.
- People: include full name and title of people you speak to where possible e.g. company Medical Information Departments/ specialist doctors/ pharmacists.
- Other electronic resources e.g. websites: specify name and/or full address of website(s) used, the date accessed and search terms used.

NB. Full address is not necessary for those websites used regularly or those listed in the minimum resources list (e.g. eMC etc.).

19. Where a drug has been appraised by the local cancer networks (Surrey Sussex and Hampshire (SWSH) Cancer Network; South West London (SWL) Cancer Network; SEC New Cancer Drugs & Therapeutics Evaluation Committee; The Pan London, South East Coast and Mount Vernon Prioritisation Group process), a summary of their recommendations should be included.

20. For rare IFR submissions check on the SEC HPSU website which contains details of IFR received by all the PCTs across the SHA. If a request is listed for the same indication the relevant PCT should be contacted directly for more information to assist processing the IFR submission (http://nww.sechealthpolicysupportunit.nhs.uk/login/) you will need to register to view this list.

21. Annotate the search with the date and identity of the processor. This must be repeated if the processor changes part way during the enquiry process.

22. IFR drugs submissions must always be processed in sufficient detail to allow a panel member to reach a decision without further contact with the enquirer. If in doubt about any aspect to the IFR clarify this with the Trust before submitting to the panel.

23. Once processed summarise at the end of the submission form Points for discussion. The following is a list of minimum points to be included in this section:
    - Reason for request – no PCT policy due to rarity or patient has demonstrated exceptional clinical circumstances
    - Comment on efficacy & safety (e.g. strength of evidence, applicability of trials etc)
    - **Comment on licensed status**
    - Comment on alternative treatments (if applicable)
    - Comment on cost effectiveness
    - Any other relevant information
    - IFR drug case prepared by

24. The date of the IFR drug panel meeting should be included in the document.

25. Panel members and persons in attendance names and titles should also be included within the document (you will find this information at the foot of the next panel's agenda or on the Y Drive/public health/prescribing/high cost & NICE drugs/Panel.

26. Prior to the IFR Drugs Panel meeting a member of the pharmaceutical commissioning team is nominated to:

- write the minutes of the meeting (to be agreed by the Chair of the IFR drugs panel)
- email the funding decision to the applying Trust
- add the funding decision to the final processed funding submission on the database and add date of communication and change the status as per the database SOP
- Write a letter to the patient (only where a funding request is DECLINED) giving the rationale for the panel's decision if required as indicated on the front of the submission form. This letter should be sent to the person indicated on the front of the submission form.

27. Where a case has been declined and resubmitted with new clinical information this case should be reconsidered at the next IFR drugs panel. All new information should be process at the end of the document under the title **Review based on new information submitted by . . . . . .** Under this section should be included the following minimum information:
    - Date new information received
    - Record of any communication post panel
    - New information provided (this should be processed in a similar way to the section on published data question 41 if relevant/applicable)
    - The name of the person preparing the review document
    - The date of panel
    - Panel members and attendants
    - Decision
    - Date decision communicated to Trust and by whom

28. Appealed IFR drug submissions with no new information should be considered by the Appeals panel.

Procedure for checking audit standards on documentation are met

1. Check all processed drug IFR submissions of new staff for adherence to documentation standards.
2. Perform annual checks to ensure that drug IFR submissions are being processed and communicated back to the requesting Trusts within the correct time frame.
3. Perform regular peer review of all processing of drug IFR submissions, including all staff.
4. All drug IFR submissions are processed by a member of the pharmaceutical commissioning team. This process is quality controlled by Guy's and St Thomas' NHS Foundation Trust's Medicines Information Centre. One IFR drug submission a month, chosen at random by Guy's and St Thomas' NHS Foundation Trust, is reviewed by a member of their Medicines Information Centre to ensure that an appropriate literature search was carried out and that the application contains an accurate summary of all relevant clinical trails / reviews as detailed in this SOP.

APPENDIX 3A - Standard Operating Procedure for Processing Intervention IFRs

Background:

IFRs for interventions are submitted to NHS Surrey by its providers (e.g. local Acute Trusts and Tertiary centres). IFRs for Interventions are processed by the Acute Contracting TNRF Team and presented to the IFR Interventions panel (fortnightly) who make a decision on funding of the requested intervention.
Complete enquiry documentation is an audit standard and allows collation of correct statistical information relating to the handling of IFR Intervention requests.

Objective/ aim of procedure

To ensure full and complete documentation is achieved for all Intervention IFRs processed by the Acute Contracting TNRF Team at NHS Surrey.

Risk Management Notes

Clear and comprehensive documentation is necessary for legal and ethical reasons, in order to ascertain exactly what information was provided, by whom and what resources were used. This also ensures that an enquiry can be located at a later date, to save time in dealing with future enquiries.

Procedure

1. Intervention IFRs for NHS Surrey should be submitted as an electronic attachment to tnrf@nhs.net. (It is the responsibility of the Acute Contracting TNRF team to check the account daily as per the tnrf@nhs.net standard operating procedure) or where Interventions IFR submission forms are hand written, these can be submitted via post or faxed to TNRF safe haven fax.

2. All Intervention IFR requests received will be checked to ensure that patient is permanently registered with a Surrey GP. A smart card is required to view the patient tracing system and all permanent members of the team will be given access to this system. This system shows the patient's GP and the PCT responsible for the patient.

3. The submission form must then be checked for completeness and that it has been approved by a suitable representative of the Trust

4. A decision about appropriateness for consideration by the IFR Interventions panel must then be made:

    - Is the request funded within the existing commissioning policy?
    - Is the request covered by another PCT policy or process?

- Does the request amount to a service development thus requiring PCT policy?

5. Before processing an IFR request check "Question 42" to see if a decision is required urgently. Where a case has been specified as urgent the processor needs to confirm this with the requesting Trust/clinician and then follow the fast-tracking urgent IFRs section of NHS Surrey Policy and Operating Procedures for dealing with IFRs (section 2.7).

6. It is the responsibility of the processor to email/write to the Trust/requester and acknowledge receipt of the IFR and to inform them of the next available panel date (unless otherwise agreed with another member of the Acute Contracting TNRF team)

7. The processor must then ensure that the Intervention IFR request is saved onto the Acute Contracting TNRF team database following the relevant procedure (see database SOP). NB: The request must be saved as a submission and then again as an NHS Surrey non patient identifiable version. This ensures that any questions raised in the future regarding the original submission can be answered.

8. Ensure that all information from the trust or parties related to the funding submission (letters, pictures etc) is anonymised.

9. Process the NHS Surrey version of the form as follows. Select all text and change to Arial, font size 10 and ensure document is set to single spacing (under format, paragraph). Ensure there are no gaps within the document and choose the double sided option when printing the document. Ensure that blank pages and contact details of PCTs at the bottom of the form are deleted (not relevant for panel discussion).

10. The processor should ensure that all relevant information is included. If there are any gaps or whilst reading the form the processor has questions or knows what the members of the panel will ask, contact the requesting clinician to seek clarification.

11. When editing the form ensure that the words 'PCT comments' are annotated into the relevant boxes (so that it is clear which information was from the Trust/GP and which came from the PCT)

12. Published data section (question 41 of submission form): This section is where the evidence for the intervention is reviewed. The following headings/information should be provided:

    - **Trust Identified Information** for all information submitted by the Trust/GP. Where links to a journal have been provided these should be replaced with the journal, title, author and dates. Where the full document can be obtained a critical appraisal of the paper must be done by the processor. If the full paper cannot be found then the

Trust should be contacted and asked whether they can forward this on.

- Where a Public Health review is provided it should include details of documents/sources accessed in the order the resources have been searched. A list of search terms used must be documented and the date the resources were accessed. Clearly state the names of all resources used, where nothing has been found, "Nil found" should be recorded.

13. If applicable additional information should be sought as follows: Public Health opinion/review.
14. People: include full name and title of people you speak to where possible e.g. company Medical Information Departments/ specialist doctors/ GP
15. If applicable, include a summary of the Health Policy Support Unit (HPSU) comments if they have considered this Intervention.
16. For rare IFR submissions check on the SEC HPSU website which contains details of IFRs received by all the PCTs across the SHA. If a request is listed for the same indication the relevant PCT should be contacted directly for more information to assist processing the IFR submission (http://nww.sechealthpolicysupportunit.nhs.uk/login/) you will need to register to view this list.
17. IFR Interventions submissions must always be processed in sufficient detail to allow a panel member to reach a decision without further contact with the enquirer. If in doubt about any aspect to the IFR, clarify this with the Trust/clinician before presenting to the panel.
18. Once processed summarise at the end of the submission form, Points for discussion. The following is a list of minimum points to be included in this section:
    - Reason for request – no PCT policy due to rarity or patient has demonstrated exceptional clinical circumstances
    - Any other relevant information
    - IFR case prepared by
19. Where possible the date of the IFR Intervention panel meeting should be included in the document.
20. Prior to the IFR Interventions Panel meeting a member(s) of the Acute Contracting TNRF team is nominated to:

    - write the minutes of the meeting
    - communicate the funding decision to the applying Trust/clinician
    - add the funding decision to the final processed funding submission on the database and add date of communication and change the status as per the database SOP
    - Copy outcome letter to the patient giving the rationale for the panel's decision, if required as indicated on the front of the submission form. This letter should be sent to the person indicated on the front of the submission form.

21. Where a case has been declined and resubmitted with new clinical information this case should be reconsidered at the next IFR Interventions panel. All new information should be process at the end of the document under the title **Review based on new information submitted by . . . . . .** Under this section should be included the following minimum information:

    - Date new information received
    - Record of any communication post panel
    - New information provided (this should be processed in a similar way to the section on published data question 41 if relevant/applicable)
    - The name of the person preparing the review document
    - The date of panel
    - Date decision communicated to Trust/GP and by whom

22. Appealed IFR Intervention submissions with no new information should be considered by the Appeals panel.

Procedure for checking audit standards on documentation are met

1. Check all processed Intervention IFR submissions of new staff for adherence to documentation standards.
2. Perform annual checks to ensure that Intervention IFR submissions are being processed and communicated back to the requesting Trusts/clinicians within the correct time frame.
3. Perform regular peer review of all processing of Intervention IFR submissions, including all staff.
4. All Intervention IFR submissions are processed by a member of the Acute Contracting TNRF team.

APPENDIX 4 – Individual Funding Requests (IFR) Drugs Panel - Terms of Reference

Purpose

- Consider Individual Funding Requests for high cost drugs
- Review complex follow up cases where the decision to approve long term funding is not straightforward
- Review decisions made for individual funding request submissions where new information is available
- Consider in part 2 of the meeting funding requests for submissions which are not appropriate for the IFR process but there is a clear clinical reason why the patient's health will be significantly compromised by waiting until a service development decision has been made.

Chairman

The panel can be chaired by any of the members provided that s/he has sat as an IFR panel member at least four times. The Chair must be identified in advance of the meeting, and must be available to approve the minutes / letters and fulfil any other obligations within the specified time frame.

Membership, delegation and probity

The membership of this committee is as follows:
Core (voting) members

- Public Health representative (e.g. Director of Public Health, Consultant in Public health or nominated deputy)
- GP from Surrey PCT
- Associate Director of Planned Care and Cancer or nominated deputy
- Head of Pharmaceutical Commissioning Team or nominated deputy
- Lay member and / or PALS representative

Members are expected to attend at least 75% of committee meetings in one year and also to send suitable directorate representation for the meetings they are unable to attend. A register of attendance at the committee will be maintained and reviewed by the committee on a 6 monthly basis.

All individuals attending a meeting, whether as a member or in attendance, must declare any potential conflicts of interest. It will be for the chair of the meeting to decide how this is managed, including asking the individual to

withdraw from the meeting in some cases where issues are discussed or decisions taken.

Frequency of meetings and quorum arrangements

- The high cost drugs panel will meet fortnightly, but the frequency may be subject to variation over time
- The venue will usually be Surrey PCT Headquarters, Leatherhead unless notified otherwise
- Four core members should be present to make a decision on a drug IFR, one of whom must be a clinician

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Accountability / dependencies with other committees and group (formal and informal)

- The IFR Drugs Panel is a Sub Committee of the Planned Care Programme Board
- The IFR Drugs Panel will provide reports quarterly to the Planned Care Programme Board on decisions taken and related expenditure.

List of dependent sub committees / groups / functions / programmes

The IFR Drugs Panel will link with the following committees/groups providing reports on the activity of the Panel as relevant to the particular committee.

- Commissioning Executive Committee
- Planned Care Programme Board
- South West London Cancer Network
- Surrey, West Sussex & Hampshire Cancer Network
- West London Cancer Network
- South East Coast Specialised Commissioning Group
- Area Prescribing Committee
- NICE implementation & clinical effectiveness sub-committee

Process for Monitoring Effectiveness of the Committee in relation to expectations set out in the terms of Reference.

Members must have attended training, and ensure that they are fully familiar with the NHS Surrey Policy and Operating Procedures for dealing with IFRs and process before sitting on a panel. Members should attend a training session at least once every two years and sit on panels at least twice a year in order to retain their qualification to serve.

The agenda and minutes of the meeting will be audited annually to ensure there is evidence the committee executed its duties as stipulated in its terms of reference and met the minimum data set of the NHSLA standard 1.1.3.

NHSLA standard	Method of review of effectiveness	Lead	Frequency of review
Duties of the committee	Review of TOR	Chair	Annually
Reporting arrangements into high level committees(if appropriate) and Board	Review of TOR	Chair	Annually
Membership including nominated deputy	Review of TOR	Chair	Annually
Required frequency of attendance.	Attendance figures	Chair	6 monthly
Quoracy of meeting	Review of minutes	Chair	Per meeting

Date and Review

The terms of reference will be reviewed at least annually

APPENDIX 4A – NHS Surrey IFR Interventions Panel - Terms of Reference

Purpose

- Consider funding submissions for IFR Interventions
- Review the evidence for cases
- Review decisions made for IFR Intervention submissions where new information is available

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Chairman

The panel can be chaired by any of the members provided that s/he has sat as an IFR panel member at least four times. The Chair must be identified in advance of the meeting, and must be available to approve the minutes / letters and fulfil any other obligations within the specified time frame.

Membership, delegation and probity

The membership of this committee is as follows:
Core members

- Associate Director - Panel Chair
- Public Health representative (e.g. Associate Director Public Health, Consultant in Public health or nominated deputy)
- GP from NHS Surrey area
- Lay representative and / or PALs

Members are expected to attend at least 75% of committee meetings in one year and also to send suitable directorate representation for the meetings they are unable to attend. A register of attendance at the committee will be maintained and reviewed by the committee on a 6 monthly basis.

All individuals attending a meeting, whether as a member or in attendance, must declare any potential conflicts of interest. It will be for the chair of the meeting to decide how this is managed, including asking the individual to withdraw from the meeting in some cases where issues are discussed or decisions taken."

Frequency of meetings and quorum arrangements

- The IFR Interventions panel will meet fortnightly, but the frequency may be subject to variation over time

- The venue will be within the boundaries of NHS Surrey
- Three core members should be present to make a decision on an exceptional circumstance funding request, one of whom must be a clinician

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Accountability / dependencies with other committees and group (formal and informal)

- The IFR Interventions Panel is a Sub Committee of the Planned Care Programme Board
- The IFR Interventions Panel will provide regular reports to the Planned Care Programme Board on submissions made to the Panel and decisions taken.

List of dependent sub committees / groups / functions / programmes

The IFR Interventions Panel will link with the following committees/groups providing reports on the activity of the Panel as relevant to the particular committee.

- Planned Care Programme Board
- Commissioning Executive Committee & PCT Board (as required)
- South East Coast Specialised Commissioning Group

Process for Monitoring Effectiveness of the Committee in relation to expectations set out in the terms of Reference.

Members must have attended training, and ensure that they are fully familiar with the NHS Surrey Policy and Operating Procedures for dealing with IFRs and process before sitting on a panel. Members should attend a training session at least once every two years and sit on panels at least twice a year in order to retain their qualification to serve.

The agenda and minutes of the meeting will be audited annually to ensure there is evidence the committee executed its duties as stipulated in its terms of reference and met the minimum data set of the NHSLA standard 1.1.3.

NHSLA standard	Method of review of effectiveness	Lead	Frequency of review
Duties of the committee	Review of TOR	Chair	Annually
Reporting arrangements into high level committees(if appropriate) and Board	Review of TOR	Chair	Annually

Membership including nominated deputy	Review of TOR	Chair	Annually
Required frequency of attendance.	Attendance figures	Chair	6 monthly
Quoracy of meeting	Review of minutes	Chair	Per meeting

Date and Review

The terms of reference will be reviewed at least annually

APPENDIX 4B – Individual Funding Requests (IFR) Appeals Panel - Terms of Reference

Purpose

Consider Appeals against decisions made by the IFR Panels (both drugs and interventions) on the grounds that:

- There was procedural irregularity in the original decision making process
- There is evidence to suggest that the IFR Panel failed to consider and take into account relevant information, or apply appropriate weighting to that information when reaching its decision.

The IFR Appeal panel will review all the documents relating to the appeal, the original IFR submission and the original IFR panel's decision, and will consider whether they are satisfied that:

- The original IFR panel acted in accordance with the PCT's approved procedures
- The decision was consistent with the SEC Ethical Framework for decision-making and the principles set out in the Policy and Operating Procedures for dealing with IFRs
- The original IFR panel properly considered the scope and nature of evidence
- In reaching its decision the original IFR panel took into account and appropriately weighed all relevant factors.

An IFR Appeal panel will not consider new evidence.

If the IFR Appeal panel decides to uphold the IFR panel's decision, the patient and his/her clinician will be advised that no further considerations can be made by NHS Surrey through the IFR process and their next recourse must be to the NHS Complaints process.

If the Appeal panel decides to overturn the original IFR panel's decision the patient and his/her clinician will be advised that their IFR submission will be reconsidered by the IFR panel, which will take account of any additional evidence which has become available in the meantime

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Chairman

The panel can be chaired by any of the members provided that s/he has sat as an IFR panel member at least four times. The Chair must be identified in advance of the meeting, and must be available to approve the minutes / letters and fulfil any other obligations within the specified time frame.

Membership, delegation and probity

The membership of this committee is as follows:

Core (voting) members

- Director of Public Health or nominated deputy (must be medically qualified); Chair
- Director of Marketing Management & Development or nominated deputy
- Non executive director
- Associate Director
- Lay member (NHS Surrey is in the process of recruiting lay member onto the Appeals panel)

During their membership of the IFR Appeal panel the above members may not also sit as members of the drug or intervention IFR panels.

Members are expected to attend at least 75% of committee meetings in one year and also to send suitable directorate representation for the meetings they are unable to attend. A register of attendance at the committee will be maintained and reviewed by the committee on a 6 monthly basis.

All individuals attending a meeting, whether as a member or in attendance, must declare any potential conflicts of interest. It will be for the chair of the meeting to decide how this is managed, including asking the individual to withdraw from the meeting in some cases where issues are discussed or decisions taken."

Frequency of meetings and quorum arrangements

- The numbers of appeals received are difficult to predict and therefore arrangements for the IFR Appeal panel meetings are worked on a flexible basis in response to demand. The IFR Appeal panel will usually meet within 20 working days of an appeal being received by NHS Surrey.
- The venue will usually be Surrey PCT Headquarters, Leatherhead unless notified otherwise
- The IFR Appeal Panel must comprise of a minimum of three members including a clinician and a PCT Director

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Accountability / dependencies with other committees and group (formal and informal)

- The IFR Appeal Panel is accountable to Risk and Clinical Governance

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List of dependent sub committees / groups / functions / programmes

The IFR Appeals Panel will link with the following committees/groups providing quarterly reports on the activity of the Panel as relevant to the particular committee.

- Risk and Clinical Governance
- Planned Care Programme Board

Process for Monitoring Effectiveness of the Committee in relation to expectations set out in the terms of Reference.

Members must have attended training, and ensure that they are fully familiar with the NHS Surrey Policy and Operating Procedures for dealing with IFRs and process before sitting on a panel. Members should attend a training session at least once every two years and sit on panels at least twice a year in order to retain their qualification to serve.

The agenda and minutes of the meeting will be audited annually to ensure there is evidence the committee executed its duties as stipulated in its terms of reference and met the minimum data set of the NHSLA standard 1.1.3.

NHSLA standard	Method of review of effectiveness	Lead	Frequency of review
Duties of the committee	Review of TOR	Chair	Annually
Reporting arrangements into high level committees(if appropriate) and Board	Review of TOR	Chair	Annually
Membership including nominated deputy	Review of TOR	Chair	Annually
Required frequency of attendance.	Attendance figures	Chair	6 monthly
Quoracy of meeting	Review of minutes	Chair	Per meeting

Date and Review

The terms of reference will be reviewed at least annually

APPENDIX 5 – Consensus Decision Making

South East Coast
Health Policy Support Unit

5 fingers: I strongly support this decision.

4 fingers: I support this decision.

3 fingers: This decision is acceptable to me but my support for it isn't particularly strong.

2 fingers: I am uncomfortable with this decision, but I can live with it.

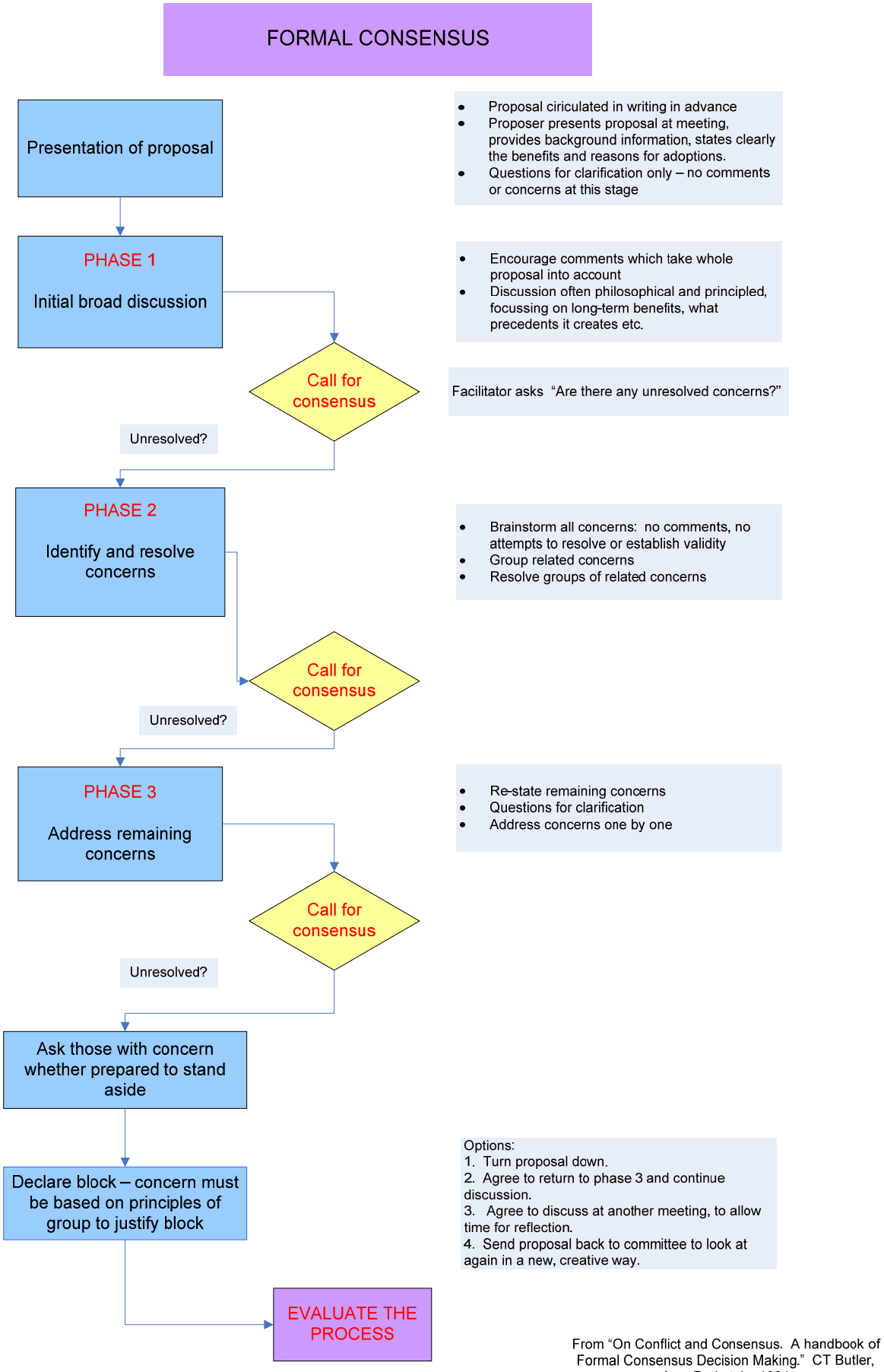
1 finger: I personally do not support this decision but I promise not to sabotage it.

Closed fist: I cannot live with this decision. I need an alternative I can live with.

From Dane County COMP Plan
Consensus Document
http://www.daneplan.org/pdf/documents/consensusdocument.pdf

43 A proposal is accepted if more than 75 percent of the potential votes are cast (i.e. fingers), and there are no fists.

Number of PRC Members Present	Number of Fingers required for 75%
17	64
16	60
15	56
14	53
13	49
12	45
11	41
10	38
9	34
8	30
7	26



From "On Conflict and Consensus. A handbook of Formal Consensus Decision Making." CT Butler, Amy Rothstein, 1991

APPENDIX 6 - SEC Ethical Framework for Decision-Making

Agreeing the important principles that will guide decision-making

Public bodies are accountable for their decisions, and should be able to demonstrate that these are reasonable. Primary Care Trusts (PCTs) are concerned to demonstrate that their decisions about health policy are based on sound principles and have been made after careful consideration of all the relevant factors, with reference to local conditions, and with a conscious intent to avoid discrimination. To this end principles for decision-making have been agreed and adopted by the South East Coast Policy Recommendation Committee.

Five principles for decision-making

Five principles for decision-making have been identified. Key principles are the need for decisions to be rational, socially inclusive, and take account of economic factors. A further principle is that the policies themselves, and the process for taking decisions to determine policy, must be clear, consistent and transparent. The fifth principle is the requirement to balance the needs of the individual with the needs of the wider community, to consider public health issues, and to encourage preventative care and health promotion measures.

Principle: Rational

Aspects of this principle include:

- Being logical in reasoning towards a decision
- Ensuring that the decision is based on evidence of clinical effectiveness
- Making a realistic appraisal of the likely benefit to patients
- Weighing up all the relevant factors, including risks and costs

The NHS is committed to evidence-based health care. Decisions should be made on the basis of a reasonable evaluation of the available evidence of clinical effectiveness. The people involved in decision-making have an obligation to seek out the best evidence of clinical effectiveness to inform their decisions. Where available, existing national standards and guidelines must be considered. Local factors and the existing care provision must also be considered.

The approach to assessing the validity and credibility of evidence should be broad but maintain high standards of critical appraisal. Both qualitative and quantitative studies will be taken into consideration, with evidence from sources other than large-scale randomised clinical trials given appropriate weight.

Outcome measures should be considered in terms of their importance to the patients. This is particularly significant in the treatment of illness where no cure can be expected, in palliative care, and the care of people who are terminally ill. Rational decisions will weigh up likely outcomes, the wider contexts in which treatments can be provided, the implications for service delivery, clinical pathways, and the scale and nature of benefits, costs and risks.

Principle: Inclusive

The term 'inclusive' may be interpreted as covering:

- Equal opportunity of access to health care
- Patient involvement in decision-making
- Respect for individual needs

Decisions about health policy should be arrived at through a fair and non-discriminatory process, and should reinforce the concept of equal opportunity in access to health care. Policies should not discriminate on characteristics, such as race, religion or social status, which are irrelevant to health conditions and the efficacy of treatment.

The aim is to achieve consistent and equitable resource allocation, between individuals and groups in society, and to avoid the kind of arbitrary discrimination summed up in the term 'post-code prescribing'.

Policies should work in favour of patient choice at the individual level, respecting the individual's preferences. In particular, the ethical framework calls for sensitivity to the patient's perspective and the individual nature of choices based on quality of life. These considerations may be particularly important in end-of-life circumstances.

Decisions should take account of local and societal sensitivities. There should be an active attempt to engage patients, carers and the wider public in the decision-making process to ensure that the perspectives of both health care providers and consumers are fully taken into account.

Principle: Take account of economic factors

Resources are finite and must be managed responsibly. The cost of treatment must be considered. Investment in one area of health care will divert resources away from other areas of potential investment. Decisions should be based on careful consideration of the trade-offs between costs and benefits, both in the short and longer term, but also recognise that complex trade-offs cannot necessarily be reduced to simple cost-benefit calculations.

In general, low-cost treatments with high effectiveness will be preferred, whereas high cost treatments with low effectiveness are to be discouraged.

Principle: Clear and open to scrutiny

Both the policies themselves, and the way they are determined, should be clearly specified, consistent, easy to understand, and open to public scrutiny.

The formal process set out for the identification, prioritisation and review of policy issues has been designed with the need for clarity and scrutiny in mind. However, members of the Committee and sub-groups undertaking this process do have a responsibility to work towards achieving these goals.

The information provided to decisions-makers should be fully documented. The process of decision-taking should also be documented, to show that it has conformed to the process agreed by South East Coast Primary Care Trusts, and to record the degree of consensus.

Principle: Promote health for both individuals and the community
Policies which promote health and avoid people becoming ill are considered alongside curative treatments and other interventions.

There may be times when it is appropriate to target some demographic groups or health issues in order to reduce inequalities and promote the well-being of the community as a whole.