The Office *of the*
Committee *for*
Health & Social Care

Individual funding requests

This document sets out the policy for dealing with individual funding requests.

The individual funding request process is designed to assess requests to access treatments not normally funded by the Committee for Health and Social Care (CHSC).

This document is linked to Policy G1033: Guiding principles, rules and policy statements to underpin resource allocation in health and social care.

There are separate policies and policy statements setting out the funding position for some individual treatments which may be relevant to individual cases.

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Committee for Health and Social Care Policy

Individual funding requests

This is a controlled document. As a controlled document, the correct version of the document is the one available on CHSC intranet and the States of Guernsey website.

Version History

Version Number	Date	Person responsible	Prepared by (title of author/reviewer)	Status	Reason for Issue
1.0	2013	Director of Public Health	Public Health Advisor	Superseded	New policy
2.0	2014	Director of Public Health	Public Health Advisor	Superseded	Minor revisions made.
3.0	Sept 2015	Director of Public Health	Public Health Advisor	Superseded	Combines IFR policy and its supporting operational policy into one policy Insertion of a new section on screening for experimental and unproven treatments Revision of aspects of the processes Insertion that allows officers to refer funding queries to the IFR process Removal of the role of IFR administrator which is not currently funded
4.0	Sept 2016	Director of Public Health	Public Health Advisor	Superseded	Full review of the policy Additional clause to enable Screening Officers to seek the view of the Panel about individual cases at

					the screening stage. 'Authorised officers' under the urgent decisions has been substituted by the term Screening Officer as all screening officers are the senior healthcare professionals involved in IFR processes G1002 is now a sub-policy document of G1033
4.1	July 2017	Director of Public Health	Public Health Advisor	Superseded	Minor amendment to section 14 to allow greater discretion in relation to informing the patient is going to Panel.
4.2	October 2017	Director of Public Health	Public Health Advisor	Adopted	Addition of another IFR Panel member in order that affordability can better be considered.

Important contact details

Application forms can be obtained from:

The States of Guernsey website

The Off Island Team

Address:
Individual Funding Requests
c/o The Off Island Team
Le Vauquiedor Office
Rue Mignot
St Andrew
Guernsey
GY6 8TW

Telephone:
01481 725241 x 4711

Safe-haven email address:
hp-sft.GuernseyInformationServicesReport@nhs.net

Applications should be sent to the following email address:
individualfundingrequests@hssd.gov.gg

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G1002

Background

The Committee for Health and Social Care (CHSC) each year receives a budget from the States of Guernsey to provide health and social care services. It has a responsibility to keep its spending within that budget and, in order to discharge this obligation; CHSC has to decide how and where those finite local resources are to be allocated.

The need and demand for health care is always greater than the resources that are available to CHSC and it is therefore not possible to meet all needs. As a result CHSC will need to prioritise the care it commissions and provides on a principled and ethical basis.

Those with responsibility for healthcare commissioning have to take decisions about priorities at three levels:

- when developing strategic plans;
- when deciding year on year which investment and disinvestments to make; and
- at the individual patient level.

The individual funding request (IFR) process is addressing decision making which can only be taken at the level of the individual patient. It is the means by which CHSC takes into account and prioritises requests for individuals with exceptional circumstances which cannot be accommodated through its other planning and resource allocation processes. Being part of CHSC's priority setting processes, the decision taken by the IFR Panel must be guided by the same principles for priority setting which underpins all other decisions of CHSC about priorities. These principles are set out in CHSC's healthcare policy *G1033:Priority setting in health and social care.* This policy requires affordability to be taken into account at all levels of decision making. Considering affordability involves assessing how much funding is available to spend (whether there is funding available to HSC to commit to unplanned expenditure and the relative priority of funding a proposal againstother competing calls on that funding.

This policy sets out the decision making framework for individuals funding requests and how they are operationally managed.

Part One – The decision making framework

1. The Policy

1.1 This policy applies to any patient for whom CHSC has responsibility for funding defined elements of their healthcare.

1.2 Clinicians and dental practitioners, on behalf of their patients, are entitled to make an IFR to CHSC for treatment that is not normally funded by CHSC, if the request satisfies the following conditions, but not otherwise:

The request does not constitute an application for a service development, and either:

(a) the patient's medical condition has rare clinical factors, which render it impossible to carry out clinical trials for the intervention in question, and the clinician therefore wishes to use an *existing treatment* on an experimental basis; [1]

or

(b) the patient is suffering from a medical condition for which

- CHSC has commissioning responsibility; *and*
- a defined healthcare policy[2] or care pathway exists; *and*
- the patient's particular clinical circumstances fall outside the criteria for funding set out in that healthcare policy;

or

(c) the patient is suitable to enter a clinical trial which requires CHSC to fund the treatment costs of the trial or to give approval prior to the patient entering the trial to fund the continuation of the treatment after the trial has been completed.[3] [4]

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[1] This IFR application represents the consideration of an exception under the G1033 policy which allows for an experimental or unproven treatment to be used outside the context of a robust clinical trial.

[2] CHSC 's policy G1033 provides that the default funding policy for a service development that CHSC has not yet put through normal priority setting processes for service developments, is not to fund that particular service devleopment.

[3] Note that CHSC will not generally fund the continuation of the treatment without prior approval.

2. Applying for an IFR

2.1 All individual funding requests must be made by the appropriate responsible clinician for the patient from either:

- the Medical Specialists Group (MSG);
- a general practitioner;
- a general dental practitioner
- an NHS provider organisation, under its formal approval mechanisms;
- a private provider of healthcare with whom CHSC has a contract; or
- CHSC's own directly provided services.

The *appropriate* clinician will vary according to the particulars of the case but in general there is a requirement that the clinician has sufficient expertise in the field to judge and compare the patient's case against other apparently similar patients.

2.2 Funding issues concerning an individual patient raised internally within CHSC may be referred to the IFR process for consideration or an opinion. These applications can only be made by a Director within CHSC or a referral from the Off Island Team.

3. Application of Policy

3.1 All individual funding requests submitted to CHSC will be subject to screening by a Screening Officer.

Screening

3.2 Screening will be used to identify those requests which are not legitimate IFRs. These include the following:

3.2.1 Experimental or unproven treatments which should be subject to proper clinical trials because there are sufficient numbers of similar individuals to conduct such a trial within the United Kingdom or a multi-centre trial in Europe.

[4] Consideration of requests to CHSC to support the treatment costs either during or after a clinical trial (which may be a trial sponsor's precondition for allowing a patient to enter a clinical trial) has been delegated to those responsible for IFR decision-making. This is because it is a decision to fund a treatment which is not normally funded at the patient level and will commit additional, often substantial, resource. The decision is therefore subject to the normal priority setting processes at the individual patient level.

3.2.2 Treatments which have a sufficient evidence base to be assigned priority for funding (namely that the benefits and risks of the treatment are adequately understood and the treatment's value for money can be estimated) and therefore are more appropriately considered to be a potential service development.

3.2.3 Requests to enter a patient in a clinical trial, when there are a number of other potentially eligible patients in the Guernsey population.

Screening to exclude requests to use a treatment that is experimental or unproven that should be subject to further clinical study

3.3 Where a funding request is for an individual treatment such as a medicine, surgical procedure or medical device policy *G1033's section on experimental and unproven treatment* will be applied to assess the stage which the treatment has reached in the process of its development. This may result in the treatment being categorised as experimental or unproven.

Consequence of a treatment being classified as an experimental or unproven treatment which should be subject to ongoing evaluation

3.4 CHSC will not consider funding treatments which are experimental or unproven outside the context of robust clinical studies, except in exceptional circumstances as set out in paragraph 1.2 of this policy.

3.5 CHSC may:

3.5.1 refuse funding, and list the treatment as one which will not be funded until such time as the required evidence is available and the treatment is able to be prioritised against competing demands; or

3.5.2 fund the patient in a UK based clinical trial, where that trial meets the criteria set out on *G1033 Section: Experimental and Unproven Treatments.*

Screening to exclude requests which represent potential service developments

3.6 Service developments include, but are not restricted to:

- New services;
- New treatments including medicines, surgical procedures and medical devices;
- New diagnostic tests and investigations;
- Quality improvements;
- Requests to alter an existing policy ('a policy variation'). A request for a policy

variation may include (without limitation) adding in an indication for treatment, expanding access to a different patient sub-group or lowering the threshold criteria for access to treatment;

- Requests to fund the treatment costs for a number of patients to enter into a clinical trial.

3.7 Requests for a treatment or service will be classified as a request for a service development when:

3.7.1 In the case of specific treatments such as a medicine, surgical procedure or a medical device there is sufficient evidence to understand the treatment's benefit, risks and cost-effectiveness; or

3.7.2 In the case of other service developments when there are likely to be a number of similar patients in the population served:

- who are in the same or similar clinical circumstances as the patient who is the subject of the request; **and**

- whose clinical condition means that they could make a similar request (regardless of whether such a request has been made); **and**

- who could reasonably be expected to benefit from the requested intervention to the same or a similar degree as the patient who is the subject of the request.

Consequence of a funding request being classified as a potential service development

3.8 The IFR Panel has no power to make policy decisions for CHSC. Accordingly, if a funding request has been classified as a potential service development, the IFR Panel has no jurisdiction to consider the application.

In those circumstances the application will not be submitted to the IFR Panel but will be subject to the usual business planning and priority setting processes of CHSC.

3.9 CHSC may, where the request has been classified as a service development:

3.9.1 refuse funding, and refer the case back to the provider organisation (which may be the provider arm of CHSC) and take no further action;

3.9.2 refuse funding, and request the provider organisation to prioritise an application for that service development and, if supported by CHSC,

invite the provider organisation to submit a business case as part of the yearly cycle for considering service developments;

3.9.3 refuse funding, and refer the request to the appropriate director within CHSC for an assessment with a view to determining its priority for funding as a service development proposal in the next financial year;

3.9.4 refuse funding, and refer the request to the appropriate director within CHSC for an immediate workup of proposals as a potential candidate for funding as a service development in the current financial year.

Screening for Incomplete Submissions

3.10 Applications which are deemed legitimate IFRs will be assessed to determine whether the request is accompanied by sufficient clinical, financial and other information to enable the IFR to be properly considered by the IFR Panel.

Where information is incomplete or insufficient the IFR will be refused and returned to the person making the application specifying why the request has been rejected. An IFR rejected as being incomplete or insufficient can be resubmitted at any point.

It is the responsibility of the person making the application to ensure that all relevant information on which they rely in support of the application is made available to the IFR Panel to enable the IFR Panel to properly evaluate and assess the IFR in accordance with the relevant policies.

Advice from the Panel at the screening stage

3.11 The Screening Officer may seek the advice of the IFR Panel at the screening stage. The details of the discussion will be documented in the screening form.

Referral to the IFR Panel

3.12 If a request;

- has not been categorised as an experimental or unproven treatment which should be subject to further evaluation; or
- has not been categorised as a service development;

and

- there is sufficient information to assess the case,

it will be forwarded to the IFR Panel for a decision unless:

(a) in the Screening Officer's reasonable opinion there is no realistic prospect that the IFR Panel will approve the request applying the criteria contained in this policy; and

(b) he/she reasonably considers that there are no other special circumstances for the request to be forwarded to the IFR Panel.

4. Assessment of an IFR which has passed screening

4.1 The IFR Panel will first confirm that the IFR is legitimate.

4.2 In assessing the **case** for funding, the IFR Panel will consider the following:

4.2.1 whether or not the patient has exceptional clinical features or circumstances compared to other apparently similar patients (from the most appropriate reference population depending on the category of IFR);

4.2.2 whether or not the benefit the patient is expected to derive from the intervention is likely to be significantly greater than that which other apparently similar patients would be likely to experience;

4.2.3 whether there is sufficient evidence to support the assertion that this patient is likely to gain additional benefit from treatment, as compared to apparently similar patients;

4.2.4 whether, on balance, there are justifiable grounds for funding this patient differently from those who will continue to be denied access to treatment;

4.2.5 when a case engages a principle laid down in G1033, [5] the IFR Panel must consider the risks associated with not acting in accordance with the principle. So, while the IFR Panel will have regard to the patient's individual circumstances, these will need to be weighed against the risks of breaching a key principle. In each case, the relevant policy should be referred to and considered;

4.2.6 whether or not CHSC can afford to fund the treatment vis-à-vis other competing demands.

Assessment in cases involving experimental and unproven treatments

4.3 Where the IFR Panel is making an assessment as to whether an IFR should be funded as an exception to CHSC's Healthcare policy G1033 Section: *Experimental and Unproven Treatments* the assessment will vary from that set out above.

4.4 Policy G0133 states that treatments that are experimental (i.e. where there is no evidence base) or unproven (i.e. where there is an insufficient evidence base to have demonstrated a positive benefit) will not normally be commissioned outside the context of a clinical trial. In considering whether to recommend funding of an experimental treatment outside of a clinical trial the IFR Panel must therefore consider:

4.4.1 whether the evidence for assessing this treatment for this condition cannot be considered through a robust clinical trial;

4.4.2 whether the patient has a rare condition, complication or clinical feature/set of features;

4.4.3 whether there is sufficient evidence to support the argument that the patient will benefit from treatment;

4.4.4 whether the expected benefit represents a significant health gain.

4.5 Rarity of itself is not a basis for agreeing an exception.

[5] Examples of this would be Pick-up Funding from an Industry Sponsored Clinical Trial which engages the principle that a third party, particularly an agent external to CHSC, cannot commit funding (and therefore affect the priorities) of CHSC without consent from CHSC.

4.6 In each case there should be evidence that supports the argument that the experimental treatment might work in the particular case.

Assessment of requests to provide treatment costs either during or after a clinical trial for an individual patient

4.7 These IFRs should be assessed in accordance with CHSC's Healthcare policy G1033 Section: *Experimental and Unproven Treatments*.

4.8 The IFR Panel shall consider:

- The potential strategic importance of the treatment to the patient group and to the health service generally. A judgment shall be made on whether the trial will address priorities for the relevant programme area.

- The status of the clinical trial including whether or not the trial has been ratified by the National Institute for Health Research and/or other relevant United Kingdom clinical and research bodies.

- The quality of the trial and whether or not it is likely to generate the information that is needed to enable those funding healthcare to reach a view on the clinical effectiveness and cost effectiveness of the treatment. Specialist advice may be sought by the IFR Panel on the methodology to be adopted within any trial.

- The ownership of the data. Trials which do not guarantee that the data will be made available in the public domain will not be considered for funding.

- The affordability and priority of the requested trial, compared to the other competing needs and unfunded service developments.

4.9 All applications must be accompanied by the trial protocol or a sufficiently detailed summary of the trial protocol when this is not available on the national trial register.

Rule of rescue

4.10 The IFR Panel will not adopt the approach described as "the rule of rescue". The fact that a patient has exhausted all treatment options available for a particular condition is unlikely, of itself, to be sufficient to demonstrate that there are exceptional circumstances. Equally, the fact that the patient is not responding to existing treatments (including drugs) where a recognised proportion of patients with the same presenting medical condition at a similar stage are, to a greater or lesser extent, refractory to existing treatments (or those drugs) is unlikely, of itself, to be sufficient to demonstrate that there are exceptional circumstances.

5. Information to be submitted to the IFR Panel

5.1 All applications must be accompanied by either CHSC's IFR application form or the NHS England's IFR application form.

This requirement may be waived at the discretion of the IFR Lead.

5.2 Any clinician submitting an IFR request must attempt to ensure that no immaterial information, including information about the social or personal circumstances of the patient or information which does not have a direct connection to the patient's clinical circumstances, is included in the application. Any information which is not relevant will be disregarded by the IFR Panel.[6]

5.3 The IFR Lead has discretion to seek further information to add information to the application form prior to the IFR being considered by the IFR Panel.

6. Approval of Individual Funding Requests

6.1 The IFR Panel shall be entitled to approve an IFR if **all** of the following conditions are met:

6.1.1 One of the conditions set out paragraph 1.2 above is met.

6.1.2 There is sufficient evidence to show that, for the applicant's patient, either

- the proposed treatment is likely to be clinically and cost-effective; or
- that the clinical trial has sufficient merit to warrant public funding.

6.1.3 That the application meets the eligibility requirement of all the relevant policies relating to that application including this policy.

6.1.4 CHSC can afford the treatment.

6.2 The IFR Panel is not required to accept views expressed by the patient or the clinical team concerning the likely clinical outcomes for the individual patient of the proposed treatment but is entitled to reach its own views on:

6.2.1 The likely clinical outcomes for the individual patient of the proposed treatment; and

[6] Clinicians are referred to the guidance notes accompanying this policy.

6.2.2 The quality of the evidence to support that decision and/or the degree of confidence that the IFR Panel has about the likelihood of the proposed treatment delivering the proposed clinical outcomes for the individual patient.

6.3 The IFR Panel may commission its own reports from any duly qualified or experienced clinician, scientist or other person having relevant skills concerning any application being put forward that the treatment is likely to be clinically effective in the case of the individual applicant.

6.4 The IFR Panel may make its approval subject to or contingent on the fulfilment of any conditions as it considers appropriate.

6.5 The IFR Panel may adjourn a decision on an individual case where the funding request presents any issue which needs substantial investigation and research to be conducted before CHSC can establish its position or where the IFR Panel considers that the panel requires additional information or research to be supplied. This may include the need to consult widely on the issue or any implications of funding the treatment. The IFR Panel will make its decision once that investigation and research has been completed.

7. Appeal of the Decision

7.1 If the IFR Panel

- have refused to approve the IFR; or
- have approved the IFR subject to conditions,

the patient, through their clinician, shall be entitled to ask that the decision of the IFR Panel be reviewed.

7.2 The IFR Review Panel shall consider whether:

7.2.1 the **process** followed by the IFR Panel was consistent with this policy;

7.2.2 the **decision** reached by the IFR Panel:

- was taken in accordance with the requirements of this policy;
- properly took into account and evaluated all the relevant evidence;
- did not take into account irrelevant factors;
- was taken by the members of the IFR Panel in good faith;
- was a decision that fell within the range of responses which the IFR

panel was reasonably entitled to reach on the application and upon the evidence submitted.

7.3 The Review Panel will consider only the following written documentation:

(a) the original IFR submitted to HSC;

(b) the records documenting the process of the request;

(c) the IFR Panel records, including the Decision Framework Document and any additional supporting information considered by the IFR Panel;

(d) the grounds submitted by the referring clinician in their request for review.

7.5 The Review Panel shall not consider any new information or receive any oral representations. If new information is submitted, which was not previously considered by the IFR Panel, this information should be assessed for reconsideration by the IFR Panel

7.6 In the event that the IFR Review Panel decide that the decision taken does not comply with the requirements described in paragraph 7.2, the IFR Review Panel shall next consider whether there was any reasonable prospect that the IFR Panel may have come to a different decision if the IFR Panel had complied in every respect with paragraph 7.2.

7.7 If the IFR Review Panel considers that there was no reasonable prospect that the IFR Panel would have come to a different decision then the IFR Review Panel shall approve the decision notwithstanding the non-compliance.

7.8 If the IFR Review Panel considers that there was a reasonable prospect that the IFR Panel may have come to a different decision if the IFR Panel had been in compliance with the requirements of clause 7.2, the IFR Review Panel shall refer the matter back to the IFR Panel for reconsideration of the decision.

7.9 The IFR Review Panel has no power to authorise funding for the IFR but it does have the power:

7.9.1 to make recommendations to the IFR Panel and/or to request an authorised officer to consider authorisation of the funding in urgent cases as if it were an application under paragraph 9.1; and or

7.9.2 to make recommendations in respect of the IFR process and any changes to that process that it considers may be desirable.

8. Co-operation of Provider Organisations

8.1 CHSC requires, and will proceed on the basis, that

8.1.1 the clinicians of all provider organisations will take HSC's healthcare policies into account in the advice and guidance given to patients prior to making a decision to submit an IFR; and

8.1.2 that **prior to the commencement of any treatment to that patient**, all proper advice will be given including all available options and care pathways to be adopted, and the consequences for that patient, in the event that funding is not approved by HSC.

8.2 HSC expects the management of all provider organisations to have oversight of the process contained in this policy and will expect every IFR to be sanctioned by the MSG, HSC, NHS or other appropriate provider management (in accordance with any formal procedure within each organisation) as being in accordance with this policy and reserves the right to return an unsanctioned IFR to the relevant provider organisation un-assessed.

8.3 If recurrent inappropriate IFR's are submitted, the matter will be referred to the Chief Secretary or another responsible officer of the relevant provider organisation for action to be taken.

9. Urgent treatment decisions

9.1 HSC recognises that there will be occasions when an urgent decision needs to be made to consider approving funding for treatment for an individual patient before an IFR Panel can be convened. The following provisions apply to such a situation.

9.1.1 An urgent request is one which requires urgent consideration and decision because the patient faces a substantial risk of dying or significant harm if that decision is not made before the next scheduled meeting of the IFR Panel.

9.1.2 A matter will not be treated as an urgent request under this paragraph 9.1 if;

- it arises as a result of a failure by the clinical team to apply for funding through the appropriate route in a timely manner; or

- where the patient's legitimate expectations have been raised by a commitment being given to provide a specific treatment to the patient by the treating clinician.

In such circumstances HSC will expect the treatment to be provided and that the provider organisation will fund the treatment.

9.2 Provider organisations must take all reasonable steps to minimise the need for urgent requests to be made through the IFR process.

9.3 Where an urgent decision needs to be made the decision will be taken by one of the screening officers who is a senior health professional..

9.4 The screening officer or the specially convened IFR Panel will as far as possible within the time constraints of the urgent situation, follow all the requirements of this policy in making the decision. The screening officer shall consider the nature and severity of the patient's clinical condition and the time period within which the decision needs to be taken. As much information about the patient's illness and the treatment requested should be provided with the IFR as is feasible in the time available.

9.5 The screening officer or the specially convened IFR Panel shall be entitled to reach the view that the decision is not of sufficient urgency that a decision needs to be made outside of the usual process and if so shall refer the IFR to be considered under the normal process.

9.6 The screening officer or the specially convened IFR Panel shall be entitled to reach the view that the request is, properly analysed under this policy, a request for a as yet unproven treatment or a service development and so should be refused funding and considered through a more appropriate mechanism.

Part two - The Process for Managing Individual Funding Requests

10. Checklist on submission of an IFR

10.1 The IFR must be submitted by a clinician directly involved in the care of a patient, unless this requirement has been waivered by the IFR Lead.

10.2 The IFR application should be complete, accurate and comprehensive. Any incomplete submissions will be returned to the clinician for any missing or incomplete information to be supplied.

10.3 All requests must be certified as having been vetted and sanctioned by the management of the responsible clinician's organisation, including the Medical Specialist Group, CHSC Medical Director or a NHS provider trust acting through that provider organisation's normal internal procedures.

11. Administration and Reporting

11.1 Requests coming to CHSC must be date stamped and logged.

11.2 CHSC is to use every reasonable effort to process requests within a maximum period of 40 working days calculated from the date of the **receipt of a completed IFR application** to the date of the letter from CHSC informing the requesting clinician of the decision of the IFR Panel. This period may be longer in cases involving complex or difficult issues or where there are other reasonable factors that prevent the process being completed within the timescales.

11.3 The evidence considered and the decision made will be recorded in writing.

12. Screening of the IFR

12.1 The IFR must be screened by one of the nominated screening officers. These are:

- The IFR Lead;
- The Director of Public Health;
- The Assistant Director, Strategy, Policy and Engagement;
- Any other senior officer temporarily appointed to act as a screening officer.

12.2 The screening officer may consider three options in respect of an IFR:

(a) to approve the request if it is covered by existing contracts or policies; or
(b) to refuse the request without reference to the IFR Panel; or

(c) to refer the request to the IFR Panel.

12.3 Where the screening officer is uncertain as to whether there is an arguable case, the case should be referred to the IFR Panel.

12.4 All decisions, including those approved without referral to the IFR Panel and those refused, made by a screening officer will be reported to, and be reviewed by, the IFR Panel at its next meeting. The IFR Panel has the right to require a screened case to be put before the Panel. Under such circumstances the case then will become an IFR under this policy.

12.5 The request should normally be screened within 10 working days of the date of receipt of a request.

12.6 If a request is refused a letter will be sent to the clinician explaining the reasons for the decision and outlining options that may be available.

Clinicians will be advised in the decision letter that at this stage of the process it is their responsibility to notify the patient or their authorised representatives of the decision and give them the opportunity to discuss the decision with that clinician.

12.7 If a requesting clinician believes they have significant new clinical evidence that they did not provide in their first submission which they reasonably consider may have made a difference to the screening decision made, then the clinician may submit a new IFR application with the new evidence.

13. Identifying Urgent Cases

13.1 A Screening Officer may determine that a case is clinically urgent at any point in time in the process after consultation with the patient's clinicians. The provisions of paragraph 9 apply.

13.2 The timing of an urgent IFR Panel will be based on the individual clinical circumstances and the risks of an adverse clinical outcome if a funding decision on treatment is delayed. An 'extraordinary' IFR meeting may then be convened or the authorised screening officer may determine the matter where it is not reasonably possible to convene and extraordinary meeting of the IFR Panel.

13.3 Ideally all urgent cases should be considered by an IFR meeting, but exceptionally, where the clinical need makes this impossible, communication via telephone or e-mail may be agreed by the authorised screening officer.

13.4 Decisions that are made urgently outside of an extraordinary or ordinary IFR Panel meeting will be reported to, and be reviewed by, the IFR Panel.

13.5 Where an urgent request is required to be considered, the Screening Officer or the extraordinary IFR Panel must continue to follow the decision making framework set out in this policy.

14. Organisation of an IFR Meeting

14.1 The convenor of the IFR Panel within CHSC (the IFR Lead) will arrange the date of the meeting and notify the clinician.

14.2 A letter will be sent to the patient notifying them that the funding application has been accepted as an IFR and that their case will be put before the IFR Panel together with information about how they can submit information to the IFR Panel.

14.3 If there is insufficient time to give the patient the opportunity to submit information the IFR Lead has discretion to defer the case to following month.

14.4 If an urgent decision is needed (usually when the patient is an inpatient), the IFR lead has the discretion to waiver notifying the patient, in favour of getting a timely decision.

14.5 In the event of a delay the clinician and the patient will be notified and given the reasons for the delay.

14.6 Neither the patient nor their authorised representatives, whether clinical or non-clinical, are entitled to attend the IFR Panel in person.

14.7 The IFR Lead may also contact other health professionals with clinical involvement in the patient's care (for example a consultant or therapist), or others with a specialist knowledge of the condition/intervention, for information, including (but not limited to) clarification of the patient's needs and the evidence base if it is considered necessary or desirable.

14.8 All evidence that has been received by CHSC in relation to a particular IFR will be made available to the Panel.

14.9 All information put before the Panel will be in anonymised form to protect confidentiality.

14.10 At any time prior to the actual hearing the Chairman of the IFR Panel may, but is not obliged to, convene a directions hearing to which it may invite the clinician making

the application and if the Chairman considers it appropriate, the patient or their guardian or carers. The directions hearing will deal with administrative issues including in particular the evidence to be put before the IFR Panel meeting. The Chairman of the IFR Panel and the screening officer shall be present at a directions hearing but other members of the IFR Panel are not required to be present.

14.11 The Directions Hearing is to ensure that the clinician or the patient has an opportunity (in difficult or complex cases) to request that specific evidence they wish to put forward is brought to the attention of the IFR Panel. The decision as to which evidence is to be considered by the IFR Panel is however ultimately a matter for the IFR Panel alone.

15. Terms of Reference of the IFR Panel

15.1 The terms of reference for the IFR Panel are set out in Appendix 2.

16. Outcome of the IFR Panel

16.1 The IFR Panel will send its decision in writing to the patient within 10 working days of the decision being made. The letter shall be signed by the person who chaired the hearing and will give succinct reasons for the Panel decision. A copy of the letter will be sent at the same time to the patient's clinician who made the application and (if different) the patients GP.

16.2 If the IFR request is approved, the IFR Lead will assess whether it is necessary to put a mechanism in place to monitor the clinical outcome in order to determine whether the treatment has resulted in benefit to the patient.

16.3 If funding is not agreed, the decision letter will outline any further options that are available which may include a reconsideration of the case or a review of the decision.

17. Recording the decision

17.1 The IFR Lead or other officer will record a summary of the discussion and the decision of the IFR Panel in the minutes of the meeting.

18. Reconsideration

18.1 If the referring clinician and or the patient (or their guardian or carer) believes that there is further relevant information that was not considered by the Panel **which was not available to them at the time of submission of the IFR**, they may ask CHSC

to reconsider the case specifically in the light of the new information. The additional information must be submitted to the IFR Lead within 20 working days of the date of the decision letter from the IFR Panel under paragraph 20.1.

18.2 A Screening Officer will determine, normally within 10 working days, whether the additional information significantly alters the prospects for the approval of funding for the IFR that was submitted to the initial IFR Panel meeting.

18.3 If the new information is considered to be significant, a further Panel meeting will be convened by the IFR Lead as soon as it can be reasonably arranged. If the new information is not considered to be significant, the patient and the referring clinician will be informed by letter with reasons for the decision not to refer the IFR back to the IFR Panel for reconsideration.

19. Initial Consideration of a Request for a Review of the IFR Panel Decision

19.1 If the patient (or their guardian or carer) or their clinician wishes to appeal against the decision then an application should be made in writing to the Chief Secretary of CHSC setting out the grounds within 20 working days of the decision letter from the IFR Panel under paragraph 21.1.

19.2 The request for a review will be initially considered by a Screening Officer. The Screening Officer will consult and be advised by a States' Law Officer.

19.3 If the Screening Officer and the Law Officer consider there is an arguable case to support the review, then arrangements will be put in place to convene a formal Review Panel meeting as soon as possible. The hearing shall be scheduled as soon as Review Panel members are all available and that all other administrative arrangements can be completed. The target shall be to hold the hearing within 20 working days of the Screening Officer accepting the request for a Review.

19.4 If the Screening Officer and the Law Officer do not accept the grounds put forward for a Review, a letter will be sent by the Chief Secretary to the referring clinician and or the patient (or their guardian or carer) explaining the reasons for the decision not to review the IFR Panel decision.

20. Organisation of an IFR Review Panel

20.1 The convenor of the IFR Panel within CHSC will arrange the date of the meeting and notify the clinician and the patient.

20.2 The IFR Review Panel will be convened as soon as is possible but not later than 20 working days from the date of screening.

20.3 In the event of a delay the clinician and the patient will be notified and given the reasons for the delay.

20.4 Neither the patient nor their authorised representatives, whether clinical or non-clinical, are entitled to attend the IFR Review Panel in person.

20.5 The responsibility for gathering the information (as set out in paragraph 7.3 required by the IFR Review Panel is the responsibility of the IFR lead.

20.6 All information put before the Review Panel will be in anonymised form to protect confidentiality.

21. Terms of reference of the IFR Review Panel

21.1 The terms of reference for the IFR Review Panel are set out in Appendix 3.

22. Outcome from the Review Panel

22.1 The Chair of the IFR Review Panel will write to the patient (and or their guardian or carer) and the clinician within 10 working days to inform them of the outcome of the Review Panel hearing. The letter will be signed by the person who chaired the Review Panel and will give succinct reasons for the Panel decision.

22.2 If the original IFR Panel decision is upheld, the IFR Lead Officer will inform the referring clinician, and the patient (and or their guardian or carer), of the remaining options.

22.3 If the Review Panel determines that the IFR panel needs to rehear the case, the case should go to the next meeting of the IFR Panel.

22.4 The IFR Panel will rehear the IFR and in doing so will formally address any detailed points raised by the IFR Review Panel. The IFR Panel is not bound to change its decision as a result of the case being referred for rehearing, but must give clear account of the points it was asked to address by the IFR Review Panel.

23. Recording the decision

23.1 An officer of CHSC will record a summary of the discussion and the decision of the IFR Review Panel.

24. CHSC complaints procedure

24.1 CHSC complaints procedure cannot be used to challenge a decision of the Screening Officer, the IFR Panel or the Review Panel. The complaints procedure can however be used if any person reasonably considers that they have not been treated in accordance with the standards of care or courtesy reasonably to be expected from CHSC, irrespective of the outcome of their case.

25. Monitoring

25.1 The IFR process will be monitored and reviewed, both to ensure that decision-making is fair and consistent, and to make sure that the IFR Panel are considering appropriate cases and in particular that both the screening of requests and the IFR Panel are working effectively.

25.2 The Chair of the IFR Panel will submit an annual report to CHSC.

25.2 The IFR process will be subjected to audit on a regular basis.

26. Accountability

The Accountable Officer for the IFR process is the Director of Public Health.

The IFR process comes under the auspices of Clinical Governance.

27. Distribution

- Health and Social Care intranet
- Health and Social Care's Off Island Team
- Medical Specialist Group
- General practitioners (through Chair of the Primary Care Committee)
- States of Guernsey website
- University Hospital Southampton NHS Foundation Trust
- Guys and St Thomas NHS Foundation Trust
- Royal Devon & Exeter NHS Foundation Trust
- Moorfields
- Salisbury

28. Review

This policy will be reviewed and updated as other policy documents relating to priority setting are developed.

The responsible officer is the Director of Public Health

29. Policy removal

The policy will be retained until such time as its replacement is ratified or it is assessed and deemed no longer relevant.

30. Effective date

2nd November 2017

Appendices

Appendix 1: The role of the IFR Lead Officer

A1/1.1 The IFR Lead is responsible for coordinating, managing and developing the IFR process, and the work of the IFR panels.

A1/1.2 Key elements of the IFR Lead's role will be:

- Managing the IFR Process and the IFR Administrators.
- Screening submissions to the IFR process, identifying service developments, and redirecting inappropriate submission as required.
- Deciding which submissions should be fast-tracked.
- Determining the additional information, specialist advice and reviews of evidence necessary to inform the panel's decision.
- Preparing papers for the IFR Panel.
- Attending IFR panel meetings in the role of advisor.
- Writing the minutes.
- Contributing to the recruitment and training of panel members.
- Contributing to the continuing development of the IFR process.
- Liaising with CHSC's committees and officers responsible for priority-setting and policy development to deal with situations where there is a lack of existing policy.

A1/1.3 The IFR Lead Officer will not sit as a member of the IFR panel but will attend the meetings in an advisory role.

A1/1.4 The IFR Lead Officer must have a clinical background and population health training.

A1/1.5 The IFR Lead Officer will be responsible for ensuring there is a single point of contact for patients and clinicians involved in the IFR and Appeal processes.

Appendix 2: Terms of Reference of the Individual Funding Request Panel

A2/1 Purpose

The Individual Funding Request Panel (IFR Panel) is a sub-committee of the Committee for Health and Social Care.

Its primary role is to take decisions about individual funding requests and provide assurance to CHSC that resource allocation is equitable, represents value for money and is in the interests of the whole population, thereby supporting the delivery of the organisational objectives. A key element of this will be consideration of the cases on the basis of evidence of effectiveness, cost effectiveness, impact on health and affordability,

The IFR Panel will normally reach its decision on the basis of all the written evidence which is provided to it, including the individual funding request form itself and any other documentary evidence which is provided to support it.

The IFR Panel may at its discretion request the attendance of any clinician to provide clarification on any issue, or request independent expert clinical advice for consideration by the Panel at a further date.

A2/2 Scheme of delegated authority

A2/2.1 The IFR Panel has delegated power under Rule 54 (3) '*Sub-Committees – other*' of the Constitution and Operation of States Departments and Committees.

A2/2.2 The IFR Panel must not make policy decisions for CHSC. This includes taking decisions relating to service developments.

A2/2.3 Any policy question arising from their considerations should be referred to the appropriate committee or person within CHSC.

A2/2.4 In taking its decisions, the IFR Panel must take affordability into account.

A2/2.5 Financial authorisation is as follows:

- The IFR Panel's authorisation limit is set at £50,000.
- Any decisions which may incur a financial cost in excess of £50,000 must be referred to the Chief Secretary of CHSC before a final decision can be made in order to assessaffordability.

A2/3 Membership and Quoracy

A2/3.1 The IFR Panel will be chaired by the Director of Public Health, or in his/her absence the Chief Pharmacist. In the absence of either the Director of Public Health or the Chief Pharmacist, the IFR Panel members at the hearing will nominate one of their members to chair the hearing.

A2/3.2 Membership of the IFR Panel will consist of the following:

- Director of Public Health
- CHSC Nurse
- CHSC Chief Pharmacist
- Medical Specialist Group Consultant
- General Medical Practitioner
- Chief Secretary nominated representative
- Lay member

A2/3.3 The IFR Lead will be in attendance. The IFR lead will present the case and act as adviser. The IFR Lead also has responsibility to ensure the discussion and the reasons behind each decision are clearly documented and any actions are agreed.

A2/3.4 The Panel is quorate if 3 members are present except in circumstances where all 3 employees of CHSC in which case a fourth members is required.

A2/3.5 Concerning appointment:

- The nurse and pharmacist will be appointed or nominated by HSC ;
- The consultant will be appointed or nominated by the Medical Specialist Group;
- The general medical practitioner will be appointed or nominated by the Primary Care Committee; and
- The lay member will be appointed by CHSC.

Those individuals who are the nominated deputies of Panel members will be permitted to attend as observers at the discretion of the Chairman.

A2/3.6 Where there is a conflict of interest concerning a particular case a member should notify the Chairman in advance of the IFR Panel hearing and shall not take part in relation to that case (and shall leave the room) and arrangements shall be made to ensure that the IFR Panel remains quorate in the absence of that member.

A2/4 Voting Rights

A2/4.1 IFR Panel members will seek to reach decisions by consensus. But if a consensus cannot be achieved decisions will be taken by a majority vote with each panel member having a single vote. If the Panel is equally split then the Chair of the Panel will have a second casting vote.

A2/5 Corporate Governance and Risk Management

A2/5.1 The IFR Panel will adhere to all the appropriate CHSC corporate governance and risk management arrangements including the development, implementation and monitoring of agreed strategies, policies and procedures.

A2/5.2 All members of the IFR Panel must undergo appropriate training organised by CHSC.

A2/6 Frequency of Meetings

A2/6.1 The IFR Panel will meet monthly if required and at least twice a year.

A2/6.2 Extraordinary meetings of the IFR Panel may be called to discuss significant issues if they are considered necessary.

A2/6.3 Virtual meetings by telephone or web conferencing may be held as and when required.

A2/6.4 The decisions made outside the regular meetings must be relayed to the next formal IFR Panel meeting for ratification and incorporation into the minutes of the IFR Panel.

A2/7 Reporting Framework

A2/7.1 The servicing, administrative and appropriate support to the Chair and members of the IFR Panel will be provided by both a nominated administrator.

A2/7.2 The Chair of the IFR Panel shall draw to the attention to CHSC any issue that requires disclosure to the Committee, or require executive action.

A2/7.3 The IFR Chair will submit an annual report to CHSC.

Appendix 3: Terms and Reference of the Individual Funding Request Review Panel

A3/1 Purpose

The Individual Funding Request Review Panel (IFR Review Panel) is a sub-committee of CHSC.

Its role is to consider appeals against decisions taken by the IFR Panel to ensure that decisions have been taken in accordance with the policies and processes of CHSC and the specific processes and jurisdiction are contained in this operational policy.

The Review Panel will normally reach its decision on the basis of all the written evidence which is provided to it.

The Review Panel may request the attendance of legal, clinical or public health expertise to clarify any points for consideration by the Panel.

A3/2 Scheme of delegated authority

A3/2.1 The IFR Review Panel has delegated power under Rule 16A '*Sub-Committees – other*' of the Constitution and Operation of States Departments and Committees.

A3/2.2 The IFR Review Panel has no power to authorise funding for an IFR but does have the right to make recommendations to the IFR Panel and/or to request an authorised officer to consider the exercise of that power in urgent cases as if it were an application under paragraph 4.

A3/2.3 The role of the Appeal Panel is not to revisit the original decision. Should new or additional information become available then the case should be reconsidered by the Individual Funding Panel.

A3/3 Membership and Quorum

A3/3.1 The Appeal Panel will be chaired by the The Chief Nurse and Director of Governance or in his/her absence another individuals will be nominated by the Chief Secretary.

A3/3.2 Membership of the IFR Review Panel will consist of three Directors/Business Partners/Heads of Service of CHSC (excluding the Director of Public Health who chairs the IFR Panel).

A33.3 All members must be in attendance to consider the meeting quorate. In the event of one of the members not being able to attend, an appropriate Assistant Director may be substituted for the absent member.

A3/3.4 An Administrator shall be present at all meetings to take minutes.

A3/3.5 A Law Officer shall be present to advise the Panel as required.

A3/4 Voting Rights

A3/4.1 The IFR Review Panel members will seek to reach a decision by consensus. If this is not possible a majority decision will be taken by vote with each member having one vote.

A3/5 Corporate Governance and Risk Management

A3/5.1 The IFR Review Panel will adhere to all the appropriate CHSC corporate governance and risk management arrangements including the development, implementation and monitoring of agreed strategies, policies and procedures.

A3/5.2 All members of the IFR Review Panel must undergo appropriate training organised by CHSC.

A3/6 Frequency of Meetings

A3/6.1 The Appeal Panel will be convened within 25 days of an appeal being received.

A3/7 Reporting Framework

A3/7.1 The decisions of the IFR Review Panel will be reported to CHSC.

Appendix 4: Guidance note

What is meant by exceptional circumstances?

CHSC must have good reasons for not adhering to approved healthcare policies or care pathways. There can be no exhaustive definition of the conditions which are likely to come within the definition of an exceptional individual case. The word 'exception' means 'a person, thing or case to which the general rule is not applicable'. However it is easy for there to be a misunderstanding by the patient or the clinical team as to what is meant by this expression.

Requests under the IFR process often argue the case that an individual should be treated differently than other apparently similar patients and their treatment should be funded when other patients will not be funded. These may relate to the moral or compassionate case for funding.

The IFR Panel should bear in mind that, whilst everyone's individual circumstances are, by definition, unique, and reasons can always be found for funding on compassionate grounds, very few patients have *clinical* circumstances which are exceptional so as to justify funding for treatment for that patient which is not available to other patients. The following points constitute general guidance to assist the Panel. However, the overriding question which the Panel needs to task itself remains: has it been demonstrated for this patient that his or her clinical circumstances are exceptional?

If a patient has a condition for which there is an established care pathway, the Panel may find it helpful to ask itself whether the clinical circumstances of the patient are such that they are exceptional as compared with the relevant subset of patients with that same medical condition.

The fact that a patient failed to respond to, or is unable to be provided with, one or more treatments usually provided to a patient with his or her medical condition (either because of another medical condition or because the patient cannot tolerate the side effects of the usual treatment) may be a basis upon which a Panel could find that a patient is exceptional.

However, the Panel would normally need to be satisfied that the patient's inability to respond to, or be provided with, the usual treatment was genuinely exceptional circumstance. For example:

If the usual treatment is only effective for a proportion of patients (even if a high proportion), this leaves a proportion of patients for whom the usual treatment is not available or is not clinically effective. If there is likely to be a significant number of patients

for whom the usual treatment is not clinically effective or not otherwise appropriate (for any reason) the fact that the requesting patient falls into that group is unlikely to be a proper ground on which to base a claim that the requesting patient is exceptional.

If the usual treatment cannot be given because of a pre-existing co-morbidity which could not itself be described as exceptional in this patient group, the fact that the co-morbidity is present in this patient and its impact on treatment options for the requesting patient is unlikely to make the patient exceptional.

The most appropriate response in each of the above 2 situations, is to consider whether there is sufficient justification (including consideration of factors such as clinical effectiveness, value for money, priority and affordability) to make a change to the policy adopted by CHSC for funding that patient pathway so that a change can be made to that policy to benefit a subgroup of patients (of which the requesting patient is potentially one such person). This change needs to be considered as a service development.

Non-clinical factors

It is common for an application for individual funding to be on the grounds that a patient's personal circumstances are exceptional. This assertion can include details about the extent to which other persons rely on the patient, or the degree to which the patient has contributed or is continuing to contribute to society. CHSC understand that everyone's life is different and that such factors may seem to be of vital importance to patients in justifying investment for them in their individual case. However, including non-clinical, social factors in any decision-making raises at least three significant problems for CHSC.

Across the population of patients who make such applications, CHSC is unable to make an objective assessment of material put before it relating to non-clinical factors. This makes it very difficult for the Panel to be confident of dealing in a fair and even handed manner in comparable cases.

The essence of an individual funding application is that CHSC making funding available on a one-off basis to a patient where other patients with similar conditions would not get such funding. If non-clinical factors are included in the decision making process, the Board does not know whether it is being fair to other patients who are denied such treatment and whose social factors are entirely unknown.

CHSC is committed to a policy of non-discrimination in the provision of medical treatment. If for example, treatment was to be provided on the grounds that would enable an individual to stay in paid work then this would potentially discriminate in favour of those working compared to not working. To offer a treatment to one patient and not another on the basis that the funded patient was working and the patient denied funding was out of work breaches CHSC 's principles underpinning decision making. Such a decision would also

set a precedent for CHSC to always favour those in work over those not currently in work. The same can be said of many other social factors such as having children / not having children, being a carer / not being a carer and so on. Requests to fund treatment for adolescents on the grounds that they wish to go to University (and therefore not funding treatment would not enable the individual to fulfil their true potential) or because of a person's role in society (e.g. professional) is also discriminatory and would contribute to social inequality.

Generally, CHSC does not take into account social factors in deciding what treatment to provide, unless a service is specifically designed to address health inequality or a prevailing inequity of access to normally provided care or treatment. It does not seek to deny treatment to smokers on the grounds that they have caused or contributed to their own illnesses through smoking, nor does it deny treatment to those injured participating in sports in which they were voluntary participants. However there will be times when personal factors have clinical relevance. Natural history of a disease for example may be influenced by age, and so therefore will prognosis.

In general, CHSC treats the presenting medical condition and does not inquire into the background factors which led to that condition as the basis on which to decide whether to make treatment available or not. The policy of CHSC is that it should continue to apply these principles in individual applications for funding approval. CHSC will therefore seek to invest in treatments based on the presenting clinical condition of the patient and not based on the patient's non-clinical circumstances.

In reaching a decision as to whether a patient's circumstances are exceptional, the Panel is required to follow the principles that non-clinical or social factors including social value judgements about the underlying medical condition or the patient's circumstances are not relevant.

Clinicians are asked to bear this Policy in mind and not refer to social or non-clinical factors to seek to support the application for individual funding.

Demonstrating that the patient's circumstances are exceptional

The onus is on the person making the request to set out the grounds clearly for the Panel on which it is said that this patient is exceptional. The grounds will usually arise out of exceptional clinical manifestations of the medical conditions, as compared to the general population of patients with the medical condition which the patient has.

These grounds must be set out on the form provided by CHSC and should clearly set out any factors which the clinician invites the Panel to consider as constituting a case of exceptional clinical circumstances. If, for example, it is said that the patient cannot tolerate the usual treatment because of the side effects of another treatment, the referring clinician must

explain how usual it is for the patient with this condition not to be able to be provided with the usual treatment. The clinician should be able to provide scientific evidence to verify their opinion on the likelihood of this situation.

If a clear case as to why the patient's clinical circumstances are said to be exceptional is not made out, then the Panel is obliged to refuse the application. The Panel recognises that the patient's referring clinician and the patient together are usually in the best position to provide information about the patient's clinical condition as compared to a subset of patients with that condition. The referring clinician is advised to set out the evidence in detail because the panel will contain a range of individuals with a variety of skills and experiences but may well not contain clinicians of that speciality. CHSC therefore requires the referring clinician, as part of their duty of care to the patient, to explain why the patient's clinical circumstances are said as to be exceptional.

The policy of CHSC is that there is no requirement for the Panel to carry out its own investigations about the patient's circumstances in order to try to find a ground upon which the patient may be considered to be exceptional nor to make assumptions in favour of the patient if one or more matters are not made clear within the application. Therefore, if a clear case of exceptionality is not made out by the paperwork placed before the IFR Panel, the panel would be entitled to turn down the application.

Multiple claimed grounds of exceptionality

There may be cases where clinicians and/or patients seek to rely on multiple grounds to show their case is exceptional. In such cases the Panel should look at each ground individually to determine (a) whether the factor was capable of making the case exceptional and (b) whether it did in fact make the patient's case exceptional. The Panel may conclude, for example, that a factor was incapable of supporting a case of exceptionality and should therefore be ignored on one ground, but it might be relevant on another ground. That is a judgment within the discretion of the Panel.

If the Panel is of the view that none of the individual factors on their own make the patient's clinical circumstance exceptional, the Panel should then look at the combined effect of those factors which are, in the Panel's judgement, capable of supporting a possible finding of exceptionality. The Panel should consider whether, in the round, these combined factors demonstrate that the patient's clinical circumstances are exceptional. In reaching that decision the Panel should remind itself of the difference between individual distinct circumstances and exceptional clinical circumstances.