

MAKING DECISIONS ON INDIVIDUAL PATIENT FUNDING REQUESTS(IFPR) (ALL WALES) POLICY

Procedure Number:	263	Supersedes:		Classification	Clinical
Version No:	Date of EqIA:	Approved by:	Date Approved:	Date made active:	Review Date:
4	143.2018	Clinical Written Control Documentation Group	8.5.2018	9.5.2018	11.8.2020

Brief Summary of Document:	To ensure that there is an open, transparent, fair, clearly understood and easily accessible process for decision making on IPFR's
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Scope	<p>This policy applies to clinical staff as well as the IPFR team.</p> <p>IPFR are defined as requests to the Health Board to fund NHS Healthcare for individual patients who fall outside the range of services and treatments that a Health Board has arranged to routinely provide or commission. This can include a request for any type of healthcare including a specific service, treatment, medicine, device or piece of equipment.</p>
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To be read in conjunction with:	380 - Interventions Not Normally Undertaken (INNU) Policy
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Owning committee/group	IPFR Team
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Reviews and updates		
Version no:	Summary of Amendments:	Date Approved:
1	New Policy	December 2014
2	Revised AW Policy	16.5.2017
3	Revised AW Policy – June 2017	Approved via CPRG Chair action 11.8.2017 pending presentation at CPRG meeting
4	Minor changes following CWCDG meeting	8.5.2018
	Revised Appendix A form (change of address only)	Uploaded 24.9.2019

Glossary of terms

Term	Definition
IPFR	Individual Patient Funding Requests
AWTTC	All Wales Therapeutic and Toxicology Centre

Keywords	IPFR, Individual patient funding requests
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1. INTRODUCTION

Continuing advances in technology, changing populations, better information and increasing public and professional expectations all mean that NHS Health Boards have to agree their service priorities for the application of their financial and human resources. Agreeing these priorities is a complex activity based on sound research evidence where available, sometimes coupled with value judgments. It is therefore important to be open and clear about the availability of healthcare treatments on the NHS and how decisions on what should be funded by the NHS are made.

However, there will be occasions that a type of healthcare is required which fall outside of what is routinely provided. In these circumstances the required healthcare may be accessible through Individual Patient Funding Request (IPFR).

2. POLICY STATEMENT

The Health Boards is required to strike the right balance between providing services that meet the needs of the majority of its population for which it is given responsibility, whilst having in place arrangements that enable it to accommodate people's individual needs.

3. AIM

The aim of the policy document is to ensure that there is an open, transparent, fair, clearly understood and easily accessible procedure which supports the decision making on IPFR's.

4. OBJECTIVES

The aim of the policy will be met through the following objectives:

- To provide a clear procedure for the application of an IPFR on behalf of a patient.
- To provide a clear governance framework for the decision making of an IPFR on behalf of a patient.
- To provides a clear procedure for challenge and appeal.

5. SCOPE

This policy applies to clinical staff as well as the IPFR team.

IPFR are defined as requests to the Health Board to fund NHS Healthcare for individual patients who fall outside the range of services and treatments that a Health Board has arranged to routinely provide or commission. This can include a request for any type of healthcare including a specific service, treatment, medicine, device or piece of equipment.

6. POLICY DOCUMENT

[NHS Wales Policy Making Decision IPFR](#)

7. RESPONSIBILITIES

7.1. Chief Executive

The Chief Executive Officer is overall responsible for ensuring the requirements within this policy are fulfilled and that all operational arrangements are in place.

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7.2. Director of Therapies and Health Science

The Director of Therapies and Health Science is responsible for ensuring that the requirements set out in this policy are fulfilled. This responsibility is delegated to the Assistant Director, Therapies and Health Science.

7.3. Medical Director

The Medical Director is responsible for ensuring that the requirements set out in this policy are fulfilled. This responsibility is delegated to the Associate Director for Professional Standards and Deputy Medical Director.

7.4. Associate Director of Professional Standards and Deputy Medical Director

The Associate Director of Professional Standards and Deputy Medical Director chairs the IPFR Panel. The Chair or Vice Chair of the IPFR Panel are authorised to make a decision outside of a full meeting of the Panel within their delegated financial limits.

7.5. IPFR Manager

The IPFR Manager fulfils the role of the Senior Officer and the IPFR Co-ordinator as described in the All Wales IPFR Policy. The IPFR Manager is responsible for the local implementation and adherence to the All Wales IPFR Policy. This includes managing the IPFR Panel meetings, reporting to All Wales Therapeutics & Toxicology Centre (AWTTC) and providing quarterly data for inclusion in the Integrated Performance Assurance Report which, following approval by the Board/Business Planning and Performance Assurance Committee (BPPAC) is made available in public domain.

7.6. IPFR Administration Team

The IPFR Administration Team is responsible for fulfilling its duties as described in the All Wales IPFR Policy. The IPFR Senior Administrator fulfils the role of the IPFR Co-ordinator in clerking the meetings to ensure a proper record of the panel discussions and decisions is made. The IPFR Senior Administrator also maintains a local electronic IPFR database and the AWTTC database. The IPFR Administration Team retains a record of the IPFR application and subsequent decision and any outcome data that is provided by the clinician. Data will be retained to help inform future planning requirements by identifying patient cohorts both at a local and national level. Data will also be used for the production of an annual report on IPFR's every year as required by the Welsh Government.

7.7. Clinicians

Clinicians are responsible for making IPFR applications if the specific individual patient clinical circumstances have changed, by describing / explaining / justifying;

- i. why the patient is likely to gain a significant clinical benefit from the proposed intervention; and
- ii. demonstrating that the value for money of the intervention for that particular patient is likely to be reasonable.

7.8. IPFR Panel

The IPFR Panel is responsible for adhering to the procedure outlined in the All Wales IPFR Policy, with particular focus on the decision making tool.

8. MONITORING

The All Wales Therapeutics & Toxicology Centre (AWTTC) is at the heart of the IPFR process supporting IPFR panels to work more cohesively, collating and monitoring all IPFR applications for appropriateness, identifying emerging trends and compiling the annual report for the process.

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8. APPENDIX A – IPFR APPLICATION FORM

<http://www.wales.nhs.uk/sitesplus/862/opendoc/251869>

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9. APPENDIX B – CLINICIAN LETTER – APPROVED

Ein cyf/Our ref:
Gofynnwch am/Please ask for:
Rhif Ffôn /Telephone:
Ffacs/Facsimile:
E-bost/E-mail:
Dyddiad/Date:

Bwrdd Iechyd Prifysgol Hywel Dda
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Hywel Dda University Health Board
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Dear *****

Patient:
Patient DoB:
Request For:

This letter is to inform you of the decision made by the Health Boards IPFR panel who considered your request at their meeting of *****

The request was considered in detail and at length by members of the panel which is chaired by a senior clinician. The decision is as follows;

IPFR Number:	
Decision:	APPROVED
Reason for Decision:	cut and paste directly from the 'explanation for decision' box on the decision record sheet
Authorisation Number:	
Cost Authorised:	

For reasons of fairness and consistency, requests are considered against the criteria of the NHS Wales Policy, Making Decisions on Individual Patient Funding Requests. More information on how decisions are made can be found in this document which can be downloaded from our website. It is also available on request from the IPFR team by telephoning 01437 834486/5.

I have also written to the patient to let them know that you have been informed of this decision. **It is your responsibility** to contact them within 5 working days to discuss the next steps in their care. I have not informed them of the decision of the panel as, following feedback from patients and clinicians; it was felt that these matters are best discussed directly between patients and their doctors.

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By submitting an IPFR request, you have also agreed to provide outcome data within a timely manner to the IPFR team on the progress of the patient regardless of the IPFR decision.

Please note:

Hywel Dda HB only authorises treatment to be commenced within a 12 month period. If for any reason treatment is deferred or suspended, there are changes to the treatment dosage, or treatment continues past the agreed period, the provider will be required to seek re-authorisation of funding from the Health Board.

It is the provider's responsibility to ensure that re-authorisation is gained prior to treatment taking place. The Health Board will not be liable to pay for any treatment carried out without the appropriate authorisation.

If you have any queries about this letter, please contact a member of the IPFR team on the above telephone number.

Yours Sincerely

**Associate Director for Professional Standards & Deputy Medical Director
Chair of the IPFR Panel**

Enc: Outcome Questionnaires

Cc Lead Cancer Pharmacist, Pharmacy Department, Bronglais General Hospital
Aseptic Lead, Pharmacy Department, Withybush General Hospital
Aseptic Lead, Pharmacy Department, Glangwili General Hospital
Aseptic Lead, Pharmacy Department, Bronglais General Hospital

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10. APPENDIX C – CLINICIAN LETTER NOT APPROVED

Ein cyf/Our ref: IPFR
Gofynnwch am/Please ask for: Karen Thomas
Rhif Ffôn /Telephone: 01437 834486
Ffacs/Facsimile: 01437 772402
E-bost/E-mail: hdd.ipfr@wales.nhs.uk
Dyddiad/Date:

Bwrdd Iechyd Prifysgol Hywel Dda
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Hywel Dda University Health Board
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Dear *****

Patient:
Patient DoB:
Request For:

This letter is to inform you of the decision made by the Health Boards IPFR panel who considered your request at their meeting of *****.

The request was considered in detail and at length by members of the panel which is chaired by a senior clinician. The decision is as follows;

IPFR Number:	
Decision:	NOT APPROVED
Reason for Decision:	cut and paste directly from the 'explanation for decision' box on the decision record sheet

Requests are turned down when, on balance, the evidence regarding any clinical benefits to the individual is not considered to be sufficient to fund the treatment. Health Board funding is limited, and unfortunately difficult decisions must sometimes be made when considering IPFR's. These decisions are never taken lightly.

For reasons of fairness and consistency, requests are considered against the criteria of the NHS Wales Policy, Making Decisions on Individual Patient Funding Requests. More information on how decisions are made can be found in this document which can be downloaded from our website. It is also available on request from the IPFR team on 01437 834486/5.

I have also written to the patient to let them know that you have been informed of this decision. **It is your responsibility** to contact them within 5 working days to discuss the next steps in their care. I have not informed them of the decision of the panel as, following feedback from patients and clinician's, it was felt that these matters are best discussed directly between patients and their doctors.

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I understand that your patient may be disappointed with the outcome of the panel and may wish to seek a review of the process followed. A copy of the review process and review form is enclosed. Should you wish to seek a review, the completed form must be received by the Health Board by *****.

By submitting an IPFR request, you have also agreed to provide outcome data within a timely manner to the IPFR team on the progress of the patient regardless of the IPFR decision.

If you have any queries about this letter, please contact a member of the IPFR team on the above telephone number.

Yours Sincerely

**Associate Director for Professional Standards & Deputy Medical Director
Chair of the IPFR Panel**

Cc , Lead Pharmacist in Aseptics, Pharmacy Department, Bronglais General Hospital

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11. APPENDIX D – PATIENT DECISION LETTER

Ein cyf/Our ref: IPFR
Gofynnwch am/Please ask for: Karen Thomas
Rhif Ffôn /Telephone: 01437 834486
Ffacs/Facsimile: 01437 772402
E-bost/E-mail: hdd.ipfr@wales.nhs.uk
Dyddiad/Date:

Bwrdd Iechyd Prifysgol Hywel Dda
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Hywel Dda University Health Board
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Dear *****

Request For: IPFR Number:

As you know, you and your clinician have made an application to the Health Board's Individual Patient Funding Request Panel (IPFR).

This letter is to inform you that the request was considered in detail and at length on ***** by members of the IPFR Panel which is chaired by a senior clinician and a decision has been made.

We have written to your clinician ***** who knows to contact you to discuss the outcome. I have not informed you of the decision of the panel as, following feedback from patients and clinicians it was felt that these matters are best discussed directly between patients and their clinicians. You should hear from your clinician within 5 working days of the date of this letter so please contact them if this has not happened.

For reasons of fairness and consistency, requests are considered against the criteria of the NHS Wales Policy, Making Decisions on Individual Patient Funding Requests. More information on how decisions are made can be found in this document which can be downloaded from our website.

If you have any questions about the process that your request has followed, the IPFR team will be pleased to help. You can telephone them on 01437 834486/5 or write to them at the above address. Please be aware that they are not medically trained and so will not be able to answer questions about your care, as these are matters that need to be discussed directly between you and your doctor.

Yours sincerely

**Associate Director for Professional Standards & Deputy Medical Director
Chair of the IPFR Panel**

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12. APPENDIX E – CHAIRS ACTION LETTER

Address

Dear (referring clinician)

Patient:

Patient DoB:

Request For:

IPFR Number:

This letter is to inform you of the decision made by the Chair of the IPFR Panel who considered this request due to its urgency. The Chair of the IPFR Panel considered this request on the **xxxx** and the decision is as follows:

Decision:

APPROVED

Reason for Decision:

cut and paste directly from the 'explanation for decision' box on the decision record sheet

Authorisation Number:

where applicable IPFR – AUTH –

Cost Authorised:

By submitting an IPFR request, you have also agreed to provide outcome data within a timely manner to the IPFR team on the progress of the patient.

For reasons of fairness and consistency, requests are considered against the criteria of the NHS Wales Policy for Making Decisions on Individual Patient Funding Requests. More information on how decisions are made can be found in this document which can be downloaded from our website. It is also available on request from the IPFR Co-ordinator by telephoning Karen Thomas on 01437 834486.

I have also written to the patient to let them know that you have been informed of this decision. **It is your responsibility** to contact them within 5 working days to discuss the next steps in their care. I have not informed them of the decision of the panel as, following feedback from patients and clinician's, it was felt that these matters are best discussed directly between patients and their doctors.

Please note:

Xxxx HB only authorises treatment to be commenced within a 12 month period. If for any reason treatment is deferred or suspended, there are changes to the treatment dosage, or treatment continues past the 12 month period, the provider will be required to seek re-authorisation of funding from the Health Board.

It is the provider's responsibility to ensure that re-authorisation is gained prior to treatment taking place. The Health Board will not be liable to pay for any treatment carried out without the appropriate authorisation.

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If you have any queries about this letter, please contact the IPFR Co-ordinator (name) by telephoning (contact details).

Yours Sincerely

Chair of the IPFR Panel

Cc Lead Cancer Pharmacist, Pharmacy Department, Bronglais General Hospital
Aseptic Lead, Pharmacy Department, Withybush General Hospital
Aseptic Lead, Pharmacy Department, Glangwili General Hospital
Aseptic Lead, Pharmacy Department, Bronglais General Hospital

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13. APPENDIX F – CHAIRS DECISION LETTER

Ein cyf/Our ref: IPFR
Gofynnwch am/Please ask for: Karen Thomas
Rhif Ffôn /Telephone: 01437 834486
Ffacs/Facsimile: 01437 772402
E-bost/E-mail: hdd.ipfr@wales.nhs.uk
Dyddiad/Date:

Bwrdd Iechyd Prifysgol Hywel Dda
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Hywel Dda University Health Board
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Dear *****

Patient:
Patient DoB:
Request For:

This letter is to inform you of the decision made by the Chair of the IPFR Panel who considered this request due to its urgency. The Chair of the IPFR Panel considered this request on ***** and the decision is as follows:

IPFR Number:	
Decision:	NOT APPROVED
Reason for Decision:	cut and paste directly from the 'explanation for decision' box on the decision record sheet

Requests are turned down when, on balance, the evidence regarding any clinical benefits to the individual are not considered to be sufficient to fund the treatment. Health Board funding is limited, and unfortunately difficult decisions must sometimes be made when considering IPFRs. These decisions are never taken lightly.

For reasons of fairness and consistency, requests are considered against the criteria of the NHS Wales Policy for Making Decisions on Individual Patient Funding Requests. More information on how decisions are made can be found in this document which can be downloaded from our website. It is also available on request from the IPFR team by telephoning 01437 834486/5.

Due to the urgency of this request we have **not** written to the patient to let them know the outcome of the decision. **It is your responsibility** to contact them to discuss the next steps in their care.

I understand that your patient may be disappointed with this decision and may wish to seek a review of the process followed. A copy of the review process and review form is enclosed. Should you wish to seek a review, the completed form must be received by the Health Board by *****.

HYWEL DDA UNIVERSITY HEALTH BOARD

By submitting an IPFR request, you have also agreed to provide outcome data within a timely manner to the IPFR team on the progress of the patient regardless of the IPFR decision.

If you have any queries about this letter, please contact a member of the IPFR Team on the telephone number above.

Yours Sincerely

**Associate Director for Professional Standards & Deputy Medical Director
Chair of the IPFR Panel**

Enc: review process

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14. APPENDIX G – REQUEST FOR REVIEW ACKNOWLEDGEMENT LETTER

Ein cyf/Our ref: IPFR
Gofynnwch am/Please ask for: Karen Thomas
Rhif Ffôn /Telephone: 01437 834486
Ffacs/Facsimile: 01437 772402
E-bost/E-mail: hdd.ipfr@wales.nhs.uk
Dyddiad/Date:

Bwrdd Iechyd Prifysgol Hywel Dda
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Hywel Dda University Health Board
Withybush Hospital
Fishguard Road, Haverfordwest,
Pembrokeshire, SA61 2PZ
Tel: 01437 764545

Dear (name of person making the review request)

Patient Name: (where applicable)
IPFR Number:

Thank you for your request for a review of an IPFR decision, received by the Health Board on

Choose from:

- I will write to you again shortly with the date that this review will be heard and the membership of the review panel.
- Unfortunately, your request does not currently contain enough information for me to determine whether the strict grounds for making a review request have been met. I would therefore be grateful if you would provide additional information as follows.....by the
- The Chair of the Review Panel and I have considered your request with great care and unfortunately we are unable to consider this for review as it does not meet the strict grounds for review as set out in the All Wales Policy. The reason for this is
.....

I understand that you may not agree with this decision and you are able to make a complaint to the Public Services Ombudsman for Wales. Further information is available on the Ombudsman's website www.ombudsman-wales.org.uk. You may also wish to seek further advice from your local Community Health Council who can be contacted on telephone number *****

Yours sincerely

IPFR Manager
On behalf of Hywel Dda University Health Board