



Agenda Item

5.2

Joint Commissioning Committee

All Wales Individual Patient Funding Request (IPFR) Policy

Dyddiad y Cyfarfod / Date of Meeting	20/05/2025
Statws Cyhoeddi / Publication Status	Open/ Public
	Choose an item.
Awdur yr Adroddiad / Report Author	Iolo Doull, Medical Director JCC
Cyflwynydd yr Adroddiad / Report Presenter	Iolo Doull, Medical Director JCC
Noddwr yr Adroddiad / Report Sponsor	Iolo Doull, Medical Director

Pwrpas yr Adroddiad / Report Purpose	For Approval Choose an item.
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Engagement (internal/external) undertaken to date (including receipt/consideration at Committee/Group)		
Committee / Group / Individuals	Date	Outcome
Chairs of the 7 Health Board IPFR panels Chair of the JCC IPFR panel IPFR Quality Assurance Group (QAG) IPFR Policy Implementation Group (PIG) Welsh Government	18/09/2024 – 13 May 2025	Endorsed

Acronyms / Glossary of Terms	
ABUHB	Aneurin Bevan University Health Board
AWTTC	All Wales Therapeutics & Toxicology Centre
CPO	Chief Pharmaceutical Officer
CTMUHB	Cwm Taf Morgannwg University Health Board
DMG	Decision Making Guide
HBs	Health Boards
IPFR	Individual Patient Funding Request
JR	Judicial Review
KC	Kings Counsel
NWJCC	NHS Wales Joint Commissioning Committee
PIG	PIG IPFR Policy implementation group
PTR	NHS Wales Putting Things Right policy
QAG	IPFR Quality Assurance Group
QC	Queens Counsel
ToR	Terms of Reference
VUNHST	Velindre University NHS Trust
WHSSC	Welsh Health Specialised Services Committee

1. SITUATION/BACKGROUND

The purpose of this report is to present the outcomes from the engagement process with key stakeholders to review the All Wales Individual Patient Funding Request (IPFR) Policy and to seek approval for the proposed changes to the policy.

1.1 All Wales IPFR Policy

The All Wales IPFR Policy is an NHS Wales policy owned by each of the seven HBs who have statutory responsibilities in relation to IPFR decisions. Each HB has its own HB IPFR Panel.

In December 2021, a request for a judicial review (JR) was made in the case of Maria Rose Wallpott (MW)- v- (1) WHSSC (hosted by Cwm Taf Morgannwg University Health Board (CTMUHB)) & (2) Aneurin Bevan UHB (ABUHB) when the JR was allowed and the decision of the WHSSC IPFR panel to refuse funding for treatment was quashed by the court. Subsequently, legal advice indicated the IPFR policy was being interpreted in such a way that was contrary to the original policy intention and the IPFR policy would need to be updated if its original and intended meaning was to be reinstated. This was in accordance with the subsequent advice from the KC that the judicial review had changed the intended meaning on the Policy and if the original meaning was to be returned then the wording of the Policy would need to be revised.

On 28 July 2022 the Chief Pharmaceutical Officer (CPO), Welsh Government (WG) wrote to WHSSC setting out a proposal for addressing the issues raised in relation to the operation of the Welsh Health Specialised Services Committee's (WHSSC's)

Individual Patient Funding Request (IPFR) Panel and the review of the [NHS Wales Policy Making Decisions on Individual Patient Funding Requests \(IPFR\)](#) (“The IPFR Policy”). Welsh Government requested that WHSSC lead a process of engagement for a de-minimis review of the Policy wording and the changes to the WHSSC IPFR panel Terms of Reference (ToR) should be undertaken with key stakeholders including the All Wales Therapeutics & Toxicology Centre IPFR Quality Assurance Advisory Group (AWTTC QAG), the Medical Directors and the Board Secretaries of each of the HBs and Velindre University NHS Trust (VUNHST).

1.2 Stakeholder Engagement Exercise

On the 8 November 2022, the JC approved the methodology for engagement for WHSSC to embark on an engagement process and were assured that the process adhered to the specific request from Welsh Government for a specific and limited review of the All Wales IPFR Policy engagement on the WHSSC IPFR panel ToR.

The stakeholder engagement process took place between the 10 and the 22 December 2022. The consultation documentation was issued to a broad range of stakeholders including the WHSSC IPFR panel, the All Wales Toxicology and Therapeutics Quality Assurance Group (AWTTC QAG), the NHS Wales IPFR Policy Implementation Group (PIG), Medical Directors and Board Secretaries of each of the HBs, Welsh Government and Velindre University NHS Trust (VUNHST). Additionally, a stakeholder engagement workshop was held on the 2 December 2022 in Cardiff and a number of engagement briefings were held.

1.3 Independent Legal Advice

David Locke QC (KC) was tasked with reviewing the wording of the IPFR policy and revising if appropriate. He noted that the text of the policy was contradicted by the accompanying Decision Making Guide (DMG).

He highlighted the important distinction in the policy between IPFR submissions where there was a relevant policy or guideline e.g. NICE or AWMSG (part a), or if there was no relevant policy or guideline (part b).

Part a) (there is policy/guidance) requires three criteria:

- 1) that the patient is significantly different from others with the same condition
- 2) that the patient will gain significantly more clinical benefit
- 3) that the intervention offers value for money.

In contrast part b) (no policy/guidance) requires only 2 criteria:

- 1) that the patient will gain significantly more clinical benefit
- 2) that the intervention offers value for money.

Unfortunately, the DMG could be interpreted as contradicting this distinction. David Locke emphasised the primacy of the 2017 policy, that the DMG was legally problematic and recommended the removal of the DMG from the policy.

There was initial resistance from the Policy Implementation Group (PIG) to the removal of the DSG, but through an iterative process in consultation with Health Boards (HBs), the IPFR Policy Implementation Group (PIG), the IPFR Quality Assurance Group (QAG) and WHSSC a revised policy (V10) was proposed where the DMG became an accompanying appendix to the policy.

Subsequently, Welsh Government highlighted a potential conflict between the NHS Wales Putting Things Right (PTR) policy and the IPFR policy and wanted clarity that the raising of a complaint under the PTR arrangements relates to the care provided before or after an IPFR decision, and not the process of making the IPFR decision. Finally the Terms of Reference for the JCC IPFR panel were to be amended and updated.

2.ASSESSMENT

In 2024, the NWJCC convened a meeting of the all the chairs of the HB IPFR panels, the chair of the JCC IPFR panel, the IPFR Quality Assurance Group (QAG), the IPFR Policy Implementation Group (PIG) and observers from Welsh Government. All wished to follow David Locke’s advice and recognised that the DMG was not part of policy. Through an iterative process minor changes were made to the policy (including a rewording of the DMG) until all were content (V12).

The PTR changes and the ToR of the JCC IPFR panel were incorporated.

Finally Welsh Legal Services advice was sought, and the final minor revisions were made based on their recommendations (V14). One HB expressed concerns but the issues have been discussed with the relevant HB ad they are content with the revised policy.

The updated policy presented at **Appendix 1** has been circulated to all of the HB Medical Directors who are content with the final document. The Joint Committee are requested to approve the revised policy, prior to it being submitted to the 7 x HBs for final approval and adoption from 1 July 2025.

Objectives / Strategy	
Dolen i Amcan (au) Strategol CBC / Link to JCC Strategic Objectives(s)	Maximise Value
Dolen i Ddeddf Llesiant Cenedlaethau'r Dyfodol – Nodau Llesiant / Link to Wellbeing of Future Generations Act – Wellbeing Goals	A Healthier Wales
	A More equal Wales

150623-guide-to-the-fg-act-en.pdf (futuregenerations.wales)	
Dolen i Hwyluswyr Ansawdd <i>(Canllawiau Statudol Dyletswydd Ansawdd (llyw.cymru)) /</i> Link to Enablers of Quality <i>(Duty of Quality Statutory Guidance (gov.wales))</i>	Whole-systems Perspective
Dolen i Feysydd Ansawdd <i>(Canllawiau Statudol Dyletswydd Ansawdd (llyw.cymru)) /</i> Link to Domains of Quality <i>(Duty of Quality Statutory Guidance (gov.wales))</i>	Equitable
	Effective Efficient Patient centred
Effaith Amgylcheddol/ Cynaliadwyedd (5R) / Environmental /Sustainability Impact (5Rs)	No - Not Applicable

Impact Assessment		
Ansawdd <i>Ydych chi wedi ymgymryd â Sgrinio Asesiad o'r Effaith ar Ansawdd? /</i> Quality <i>Have you undertaken a Quality Impact Assessment Screening?</i>	Yes: <input checked="" type="checkbox"/>	No: <input checked="" type="checkbox"/>
	Outcome:	Access to IPFR has the potential to increase quality
Cydraddoldeb <i>Ydych chi wedi ymgymryd â Sgrinio Asesiad o'r Effaith ar Gydraddoldeb? /</i> Equality	Yes: <input type="checkbox"/>	No: <input checked="" type="checkbox"/>
	Outcome:	Access to IPFR has the potential to increase equality of access

<i>Have you undertaken an Equality Impact Assessment Screening?</i>		
Cyfreithiol / Legal	Yes (Include further detail below)	
	The document is based on advice from counsel David Locke KC and Welsh Legal Services.	
Enw da / Reputational	There is no direct impact on the reputation of the Joint Committee as a result of the activity outlined in this report.	
Effaith Adnoddau <i>(Pobl /Ariannol) /</i> Resource Impact <i>(People / Financial)</i>	There is no direct impact on resources as a result of the activity outlined in this report.	

1. RECOMMENDATIONS

The Joint Committee is asked to:

- **Note** the report,
- **Approve** the updated All Wales Individual Patient Funding Request (IPFR) policy; and
- **Note** that once the Joint Committee have approved the policy it will be presented to the 7 x Health Boards (HBs) and Welsh Government for final approval and adoption from 1 July 2025.

2. NEXT STEPS

Inform the Health Board Medical Directors
 Inform the Health Board IPFR chairs
 Inform the IPFR Policy Implementation Group
 Inform the IPFR Quality assurance Group
 Inform Welsh Government