

2023-01-08 Extraordinary Joint Committee

Tue 01 August 2023, 13:00 - 13:30

Agenda

13:00 - 13:00 1. PRELIMINARY MATTERS

0 min

 0.0 Extraordinary JC Public Agenda 1 August 2023.pdf (1 pages)

1.1. Welcome and Introductions

Oral *Chair*

1.2. Apologies for Absence

Oral *Chair*

1.3. Declarations of Interest

Oral *Chair*


13:00 - 13:00 2. ITEMS FOR CONSIDERATION AND / OR DECISION

0 min

2.1. All Wales Individual Patient Funding Request (IPFR) Panel Chair Recruitment

Att. *Chair*

 2.1 All Wales Individual Patient Funding Request (IPFR) Panel Chair Recruitment.pdf (5 pages)

 2.1.1 Appendix 1 - Appointment Process for the IPFR and Appendices.pdf (22 pages)

13:00 - 13:00 3. CONCLUDING BUSINESS

0 min

3.1. Any Other business

Oral *Chair*

3.2. Date of Next Meeting

Oral *Chair*



**WHSSC Joint Committee Meeting held in public
Tuesday 1 August 2023 at 13:00hrs**

Microsoft Teams

AGENDA

ITEM	LEAD	PAPER / ORAL	TIME
1.0 PRELIMINARY MATTERS			
1.1 Welcome and Introductions	Chair	Oral	
1.2 Apologies for Absence	Chair	Oral	13:00 -
1.3 Declarations of Interest	Chair	Oral	13:05
2.0 ITEMS FOR CONSIDERATION AND / OR DECISION			
2.1 All Wales Individual Patient Funding Request (IPFR) Panel Chair Recruitment	Chair	Att.	13.05 - 13.15
3.0 CONCLUDING BUSINESS			
3.1 Any Other Business	Chair	Oral	
3.2 Date of Next Meeting (Scheduled) - Development Session 11 September 2023 - WHSSC Joint Committee 19 September 2023	Chair	Oral	13:15 - 13:20



Report Title	All Wales Individual Patient Funding Request (IPFR) Panel Chair Recruitment		Agenda Item	2.1	
Meeting Title	Joint Committee		Meeting Date	01/08/2023	
FOI Status	Public				
Author (Job title)	Committee Secretary & Head of Corporate Services				
Executive Lead (Job title)	Managing Director, Specialised and Tertiary Commissioning Services				
Purpose of the Report	The purpose of this report is to provide the Joint Committee (JC) with an proposal regarding the recruitment of an WHSSC IPFR Panel Chair in line with the WHSSC IPFR Panel Terms of Reference (ToR) as agreed in March 2023 but in the absence of support for the proposed changes to the All Wales IPFR Policy which was deferred at the July 2023 JC meeting				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input checked="" type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input checked="" type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s):					
Members are asked to:					
<ul style="list-style-type: none"> • Note the rationale for the eligibility requirements of the role of WHSSC IPFR Panel Chair contained within the ToR agreed in March 2023; • Note that the current Chair will no longer be eligible for the role in September 2023 and the urgent need to proceed with a recruitment process; • Support WHSSC to take forward the urgent recruitment of an IPFR Panel Chair; and • Approve the associated remuneration package for both the Chair and Lay Members. 					

INDIVIDUAL PATIENT FUNDING REQUEST (IPFR) UPDATE

1.0 SITUATION

The WHSSC Joint Committee (JC) approved changes to the WHSSC IPFR panel ToR in March 2023 in accordance with the WHSSC governance arrangements and a letter from the Chief Pharmaceutical Officer from July 2022. The ToR sit within the All Wales IPFR Policy, which was due to be considered at the July 2023 meeting of the JC and was deferred. This was because issues were raised immediately before the meeting by the Board Secretaries Peer Group regarding the integrity of the previous approval process. This matter is being taken forward outside the JC.

There is however an urgent need to progress the recruitment process for the Chair of the WHSSC IPFR Panel as the current Chair will no longer be eligible for the role in September 2023 and the current Vice Chair, who has previously undertaken the role, stepped down from the acting Chair role because she did not have sufficient time capacity. We therefore will have no Chair of the IPFR Panel from September 2023 if no action is taken.

2.0 BACKGROUND

The change specifically made relating to the Chair of the WHSSC IPFR Panel ToR in the original version and the subsequent version of the ToR agreed by the JC in March 2023 is summarised below as a reminder – the change removes the requirement that the Chair is drawn from existing members of NHS organisations' Boards and instead is drawn from open recruitment:

WHSSC IPFR Panel ToR (as included in 2017 All Wales IPFR Policy)	WHSSC IPFR Panel ToR (as agreed by Joint Committee, March 2023)
Independent Chair (who will be from existing members of the NHS organisations Boards)	Independent chair (from open recruitment)

3.0 ASSESSMENT

The rationale behind this change is that it addresses the recommendations of the independent Barrister who was invited to observe a Panel meeting and provide feedback following a judicial review. In addition it reflects advice from previous Chairs and the WHSSC Medical Director. Specifically it opens up the process to a wider pool of applicants and makes clear the skills and attributes necessary to effectively carry out the role.

Our understanding is that no concerns have been raised regarding this element of the ToR.

To support this appointment process and strengthen the Panel the view of WHSSC officers is that the post should be remunerated. The rationale for this and the remuneration of lay members is outlined in a separate paper (attached as **Appendix 1**) that was due to be considered at the July 2023 JC meeting.

4.0 RECOMMENDATIONS

Members are requested to:

- **Note** the rationale for the eligibility requirements of the role of WHSSC IPFR Panel Chair contained within the ToR agreed in March 2023;
- **Note** that the current Chair will no longer be eligible for the role in September 2023 and the urgent need to proceed with a recruitment process;
- **Support** WHSSC to take forward the urgent recruitment of an IPFR Panel Chair; and
- **Approve** the associated remuneration package for both the Chair and Lay Members.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Governance and Assurance
Link to Integrated Commissioning Plan	Approval Process
Health and Care Standards	Governance, Leadership and Accountability
Principles of Prudent Healthcare	Public & professionals are equal partners through co-production Choose an item. Choose an item.
NHS Delivery Framework Quadruple Aim	People in Wales have better quality and accessible health and social care services, enabled by digital and supported by engagement People in Wales have improved health and well-being with better prevention and self-management Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	Governance: to be a well-governed organisation with high standards of assurance, responsive to members and stakeholders in transforming services to improve patient outcomes
Finance/Resource Implications	No impact in this area was identified.
Population Health	Not Applicable
Legal Implications (including equality & diversity, socio economic duty etc)	Responsibility for appointing chairs to sub committees generally lies with the Joint Committee, as outlined in the WHSSC standing orders: <i>4.0.8 - The membership of any joint sub committees – including the designation of chair, definition of member roles and powers and terms and conditions of appointment (including remuneration and reimbursement) – will usually be determined by the Joint Committee, subject to any specific requirements, regulations or directions agreed by the LHB’s or Welsh Ministers.</i> The IPFR panel ToR, stipulate that the Chair of the panel shall be appointed by the Chair of WHSSC.
Long Term Implications (incl. WCFG Act 2015)	Not applicable

Report History (Meeting/Date/ Summary of Outcome)	14 March 2023 – Joint Committee approved updated WHSSC IPFR Panel TOR 8 November 2023 – Joint Committee IPFR Engagement Update 18 July 2023 – Report was deferred and not considered
Appendices	Appendix 1 – Appointment Process for the Individual Patient Funding Request (IPFR) Panel and Appendices



2.1.1 Appendix 1

Report Title	Appointment Process for the Individual Patient Funding Request (IPFR) Panel	Agenda Item	3.8		
Meeting Title	Joint Committee Joint Committee	Meeting Date	18/07/2023		
FOI Status	Open				
Author (Job title)	Committee Secretary & Head of Corporate Services				
Executive Lead (Job title)	Committee Secretary & Head of Corporate Services				
Purpose of the Report	The purpose of this report is to propose a recruitment process for the Chair and lay member positions of the All Wales Individual Patient Funding Request (IPFR) panel and to propose that the roles are remunerated.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input checked="" type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input checked="" type="checkbox"/>	INFORM <input checked="" type="checkbox"/>

Recommendation(s)

Members are asked to:

- **Note** the report,
- **Approve** the recruitment process for the appointment of the Chair and lay members to the All Wales Individual Patient Funding Request Panel,
- **Discuss** and **approve** the additional annual cost of remunerating the Chair of the IPFR panel and approve an uplift to the Direct Running Costs (DRC) budget to enable a financial pool of resource to recurrently fund the remunerated position; and
- **Discuss** and **approve** the additional annual cost of remunerating the two Lay Members of the IPFR panel and approve an uplift to the Direct Running Costs (DRC) budget to enable a financial pool of resource to recurrently fund the remunerated positions; and
- **Note** that once agreed with HBs, the updated process and accompanying documents will be shared with Welsh Government prior to adoption for assurance.

APPOINTMENT PROCESS FOR THE INDIVIDUAL PATIENT FUNDING REQUEST (IPFR) PANEL

1.0 SITUATION

The purpose of this report is to propose a recruitment process for the Chair and lay member positions of the All Wales Individual Patient Funding Request (IPFR) panel and to propose that the roles are remunerated.

2.0 BACKGROUND

2.1 IPFR Panel Governance Framework

The purpose of the WHSSC IPFR Panel is to act as a Sub Committee of WHSSC and hold delegated Joint Committee authority to consider and make decisions on requests to fund NHS healthcare for patients who fall outside the range of services and treatments that a Health Board (HB) has agreed to routinely provide.

The Governance framework for the WHSSC IPFR panel is outlined within the "All NHS Wales Policy Making Decisions on Individual Patient Funding Requests (IPFR)", published in June 2017 which includes specific terms of reference (ToR) for the WHSSC IPFR Panel (Panel).

Responsibility for appointing chairs to sub committees generally lies with the Joint Committee, as outlined in the WHSSC standing orders:

4.0.8 - The membership of any joint sub committees – including the designation of chair, definition of member roles and powers and terms and conditions of appointment (including remuneration and reimbursement) – will usually be determined by the Joint Committee, subject to any specific requirements, regulations or directions agreed by the LHB's or Welsh Ministers.

2.2 History - Chair of the IPFR Panel

Professor Vivienne Harpwood was the Chair of the IPFR Panel between 25 January 2017 and 1 April 2022. Upon stepping down from the role she cited the growing time commitment and complexity of the role and competing pressures from her HB role for her decision. The Joint Committee noted this growing time pressure and the need to give consideration to remuneration of the Chair in the report submitted to the Committee on [15 May 2022](#).

Since Professor Harpwood stepped down from the role there have been two interim non-remunerated Chairs, the first of whom stepped down because of the required time commitment. Currently there is an interim non-remunerated Chair whose tenure has been extended on two occasions whilst the IPFR Panel ToR and All Wales Policy engagement process was underway. Most recently the Joint

Committee approved that the interim arrangement was extended from 31 March 2023 to 30 September 2023.

The ToR for the panel, approved by the Joint Committee on 14 March 2023, including the duties of the Chair are presented at **Appendix 1** for information.

3.0 ASSESSMENT

3.1 Review of the IPFR Governance Framework

As a result of a judicial review, which quashed a decision of the All Wales IPFR Panel in December 2021, expert legal and professional advice was taken. In addition, discussion was undertaken with Welsh Government (WG) and the Medical Directors Peer Group. On 28 July 2022, the Chief Pharmaceutical Officer (CPO) on behalf of WG, wrote to WHSSC and requested that WHSSC lead a process of engagement for a specific and limited review of the All Wales IPFR policy wording, and changes to the WHSSC IPFR Panel ToR. They also noted that approval of the ToRs of the Panel were within the authority of the Joint Committee, however approval of the All Wales Policy remained with HBs (Item 3.7 IPFR Governance Update, **Appendix 1**, IPFR Governance update report [6 September 2022](#)).

WHSSC subsequently led a stakeholder engagement process between 10 November 2022 and 22 December 2022. During this process, the roles of the Chair of the Panel and lay members were highlighted and the importance of appointing a substantive chair with the relevant skills, experience, and with a specific remit and term of office was emphasised. This is also relevant to lay members. Arrangements in NHS England (NHSE), All Wales Medicines Strategy Group (AWMSG) and Health Technology Wales (HTW) for lay representation were also considered.

Following the engagement process, new TORs were approved by the Joint Committee on 14 March 2023, and the amended policy will be considered by the Joint Committee on 18 July 2023. Subject to approval, the ToRs and the policy will be submitted to HBs for final approval in keeping with the previous approaches taken by WHSSC when making complex or contentious decisions and in keeping with WHSSC's SOs.

The letter from WG also advised that they fully supported move to appoint a remunerated chair for WHSSC's IPFR panel and were agreeable to further discussions on this – see **Appendix 2**.

3.2 Chair - Recruitment Process

WHSSC is responsible for recruiting the Chair role on behalf of the JC and in accordance with the process followed to recruit the Chair of the Welsh Kidney Network (WKN), the role does not need to be advertised through the formal public

appointments process, and can be advertised via NHS Jobs website (and others as appropriate).

The updated current ToR states that an “Independent Chair” will be from “open recruitment”. This reflects:

- the feedback from the previous long serving Chair and feedback from the QC barrister invited to review the Panel process, which emphasised the importance of any future Chair requiring a comprehensive skill set, including the ability to undertake highly complex reasoning, to have a sound knowledge of the ethical principles underpinning the decision-making process,
- The barrister’s feedback also emphasised the importance of an ability to effectively manage a meeting with varied membership of health professionals and lay people,
- the fact that the time commitment of the Chair’s role has become more onerous, due to the increasing number and complexity of cases, as well as the impact of the Judicial Review which has further increased the complexity of the decision making, requiring dedicated time and focus; and
- The current assessment that meetings will continue to be held once per fortnight for half a day as a minimum.

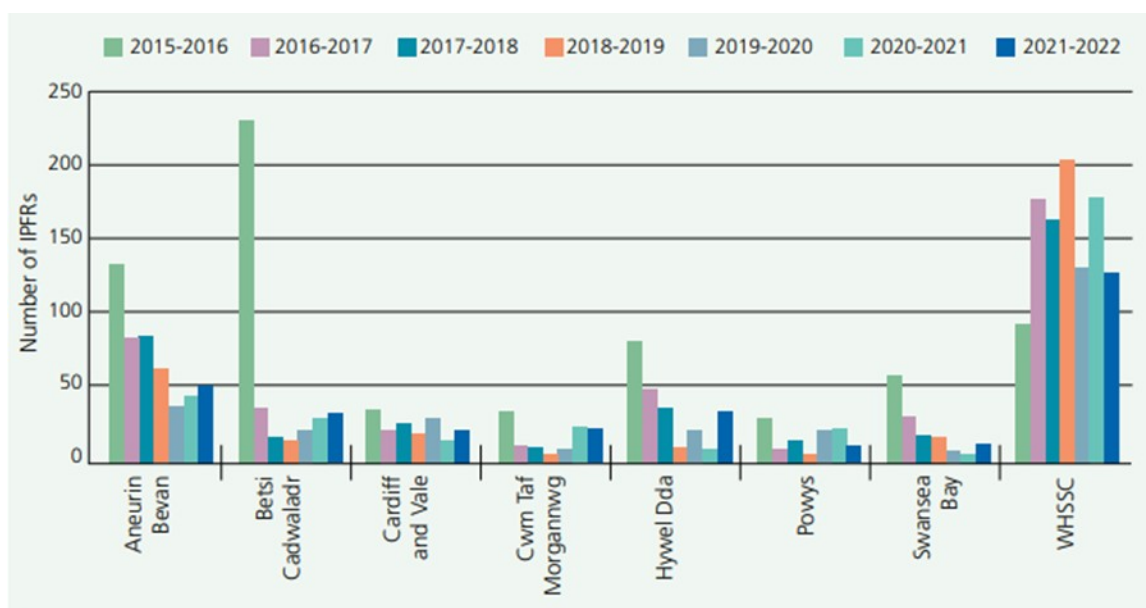
3.3 Chair Remuneration - Context and Recruitment Process

Currently there is no reference within the ToR to remunerating the Chair position. However, feedback obtained during the engagement process, from the previous chair and WHSSC’s observations of the arrangements for similar roles in Wales and in NHSE, suggest that in order to recruit into the post successfully and to deliver the requirements identified above, it is likely that remuneration will be required. Of note, the Chairs of HB IPFR Panels are either Clinical Executives or specifically appointed health care professionals and therefore specific remuneration is not required.

The Chair of WHSSC and the Committee Secretary met with WG officials on 31 May 2023 to discuss remunerating the chair and lay member positions. Discussion included fairness, equity and potential comparisons with other roles, including:

- Chair of the Welsh Kidney Network (WKN) – the WKN is a sub-committee of the Joint Committee and the chair position has been remunerated since 2009,
- Feedback from the KC barrister observing the IPFR Panel after the judicial review advised “*Strong informed chairing is of key importance*”
- The letter from the CPO in July 2022 requesting WHSSC undertake the review of the ToRs of the Panel supported remuneration of the Chair (**Appendix 2**); and
- In comparison with the HBs the WHSSC IPFR panel consider significantly more IPFR applications, as outlined in Table 1 below:

Table 1 – Number of IPFR’s within each Health Board in Wales, including WHSSC 2015-2022



Source: AW TTC Annual IPFR Report 2021-2022

As the IPFR Panel is a subcommittee of the Joint Committee, it is proposed that the Chair continue to be appointed by the Chair of WHSSC. The draft job description is presented at **Appendix 3** for information. It is proposed that the roles are advertised via the NHS jobs website and other targeted recruitment websites as appropriate.

Once approved the WHSSC IPFR panel ToR will be updated to clarify the role, tenure and remuneration of the IPFR Chair position, prior to being shared with HB’s and WG.

3.4 Lay Members – Recruitment Process

The IPFR ToR prescribe that there are two independent lay members on the panel (*Note: they must not be registered as a healthcare professional, either lay (not currently a healthcare worker) or lay plus (no healthcare experience ever) (Health Research Authority (HRA) 2014) will be eligible).*

The draft job description is presented at **Appendix 4** for information. It is proposed that the roles are advertised via the NHS jobs website and other professional and third sector websites to ensure maximum reach.

To ensure effective governance it is proposed that the lay members shall be appointed by the Chair of WHSSC in conjunction with the Chair of the IPFR panel.

4.0 FUNDING OF THE REMUNERATION PACKAGE

4.1 IPFR Budget

IPFR application approvals made by the WHSSC IPFR panel amount to circa £1.5M per annum of new costs. It is important to note that where an approval applies to a medicine this can represent significant recurrent costs over the life time of the patient.

4.2 IPFR Chair Remuneration

Following discussions with former and current IPFR Chairs and WG officials, the required time commitment of the Chair of the IPFR panel has been estimated to be 3 days per month.

In order to assess the appropriate remuneration rate for the Chair a benchmarking exercise considering a number of other related roles has been undertaken:

- The WHSSC Chair - The WHSSC Chair is remunerated at £322 per day,
- WHSSC IMs - the WKN Chair and WHSSC IMs are remunerated at £278 per day,
- NHSE Individual Funding Request (IFR) panels - Chairs are paid approximately £150 per day; and
- In addition, the remuneration rate would also need to align with the rates paid to IPFR lay members.

4.3 Lay Members Remuneration

The time commitment of a lay member of the IPFR panel has been estimated to be two days per month.

To decide the appropriate remuneration rate for the lay members a benchmarking exercise considering a number of other related roles was undertaken:

- Lay hospital managers - The lay hospital manager is a statutory role as defined in the Mental Health Act 1983 (the Act) and provides a safeguard for those patients who are detained under the Act or subject to community treatment orders. They act on behalf of the HB but are independent to the hospital. The current rate is £50 per half day panel; and
- IFR NHSE – lay members can claim for an involvement payment of £150 for a preparation day and £150 for the Panel meeting attended (this is subject to the Panel meeting taking place as scheduled).

These costs for both the Chair and lay members would need to be met from WHSSC's Direct Running Cost (DRC) budget and an uplift will be required to fund this.

Given the benchmarking information provided above it is proposed that:

- **Lay Members** - the two lay members are each remunerated at £45 per half day for 2 days per month i.e. full day £90, £360 per month at a total of £4,320 per year; and

- **IPFR Chair** - the Chair is remunerated at £160 per day for 3 days per month i.e. full day £160, £480 per month at a total of £5,760 per year. The 3 day time commitment includes additional time for preparation, chairing the meeting, attending pre-meetings, attending chairs action meetings if required, revising in detail the written record of the meeting and reviewing, approving the chairs report and attending Joint Committee and sub committee meetings where appropriate.

The Joint Committee are requested to approve the additional annual cost of remunerating the Chair and two lay member positions and approve an uplift to the DRC budget of £10,080 to enable a financial pool of resource to recurrently fund these positions. If approved the additional cost will be added to the approved Integrated Commissioning Plan (ICP) for completeness.

5.0 GOVERNANCE & RISK

The risk of not strengthening and investing in the IPFR panel relates not only to ensuring effective decision-making and ensuring the best use of the IPFR budget but to reducing the risks of challenge including judicial review. The legal costs alone of the judicial review related to the "Wallpott" IPFR decision in December 2021 were approximately £250k. In addition, there is the reputational harm to NHS Wales.

6.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report,
- **Approve** the recruitment process for the appointment of the Chair and lay members to the All Wales Individual Patient Funding Request Panel,
- **Discuss** and **approve** the additional annual cost of remunerating the Chair of the IPFR panel and approve an uplift to the Direct Running Costs (DRC) budget to enable a financial pool of resource to recurrently fund the remunerated position; and
- **Discuss** and **approve** the additional annual cost of remunerating the two Lay Members of the IPFR panel and approve an uplift to the Direct Running Costs (DRC) budget to enable a financial pool of resource to recurrently fund the remunerated positions; and
- **Note** that once agreed with HBs, the updated process and accompanying documents will be shared with Welsh Government prior to adoption for assurance.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Governance and Assurance Governance and Assurance Choose an item. Choose an item.
Link to Integrated Commissioning Plan	Approval process
Health and Care Standards	Governance, Leadership and Accountability Governance, Leadership and Accountability Choose an item. Choose an item.
Principles of Prudent Healthcare	Public & professionals are equal partners through co-production Public & professionals are equal partners through co-production Choose an item. Choose an item.
Institute for HealthCare Improvement Quadruple Aim	Improving Patient Experience (including quality and Satisfaction) Improving Patient Experience (including quality and Satisfaction) Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	Governance: to be a well-governed organisation with high standards of assurance, responsive to members and stakeholders in transforming services to improve patient outcomes.
Finance/Resource Implications	No impact in this area was identified.
Population Health	Not applicable
Legal Implications (including equality & diversity, socio economic duty etc)	<p>Responsibility for appointing chairs to sub committees generally lies with the Joint Committee, as outlined in the WHSSC standing orders:</p> <p><i>4.0.8 - The membership of any joint sub committees – including the designation of chair, definition of member roles and powers and terms and conditions of appointment (including remuneration and reimbursement) – will usually be determined by the Joint Committee, subject to any specific requirements, regulations or directions agreed by the LHB's or Welsh Ministers.</i></p> <p>The IPFR panel ToR, stipulate that the Chair of the panel shall be appointed by the Chair of WHSSC.</p>

Long Term Implications (incl WBFG Act 2015)	Not applicable
Report History (Meeting/Date/ Summary of Outcome)	14 March 2023 – Joint Committee approved updated WHSSC IPFR Panel TOR 8 November 2023 – Joint Committee IPFR Engagement Update
Appendices	Appendix 1 – All Wales IPFR Terms of Reference (ToR) Appendix 2 – Letter from Welsh Government to WHSSC Individual Patient Funding Request (IPFR) Panel – Terms of Reference, July 2022 Appendix 3 - Draft Job Description Chair of the IPFR panel Appendix 4 – Draft Job description IPFR Panel Lay Member

3.8.1 Appendix 1



TERMS OF REFERENCE – WHSSC IPFR PANEL v 1 (JC approved)

1. PANEL PURPOSE

The Welsh Health Specialised Services Committee (WHSSC) Individual Patient Funding Request (IPFR) Panel (*“the Panel”*) is constituted to act as a Sub-Committee of the Welsh Health Specialised Services Committee (*“the Joint Committee”*) and holds delegated Joint Committee authority to consider and make decisions on requests to fund NHS healthcare for patients who fall outside the range of services and treatments that a Health Board (HB) has agreed to routinely provide.

The IPFR panel will act at all times in accordance with the All Wales IPFR Policy taking into account the appropriate funding policies agreed by WHSSC.

The IPFR Panel will normally reach its decision on the basis of all the written evidence, which is provided to it, including the request form itself, and any other documentary evidence, which is provided in support of the application. The IPFR 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. The provision of appropriate evidence to the Panel will be entirely at the Panel Chair’s discretion.

1.1 IPFR Panel Authority

The IPFR Panel cannot make policy/commissioning decisions for the HB. Any policy proposal arising from the Panel’s consideration and decisions will be reported to the WHSSC Management Group and/or the Joint Committee for ratification.

The financial authorisation limit is set at £750,000 for one off patient packages and £1 million for lifetime packages.

Any decisions resulting in a financial cost in excess of these limits must be reported to the Managing Director of Specialised and Tertiary Services for authorisation and the relevant Health Board for information and if over £1 million to the Joint Committee for approval or ratification (if a chairs action was undertaken).

2. MEMBERSHIP

The IPFR panel will have a core membership of:

- Independent chair (from open recruitment 2 Lay representatives **
- HB IPFR Panel Chairs from each of the 7 Health Boards or nominated clinical deputy
- 2 vice chairs (appointed from within the panel membership)
- WHSSC Medical Director or nominated deputy
- WHSSC Director of Nursing, or nominated deputy

A further two panel members from the NHS in Wales may be appointed at the discretion of the Chair of the Panel in conjunction with the WHSSC Medical and / or Director of Nursing, for example, a member of an ethics committee.

In attendance from WHSSC:

- IPFR Manager/co-ordinator
- Finance Advisor (if required)
- Head of Corporate Governance
- Other WHSSC staff as and when required to clarify on policy/commissioning arrangements/evidence evaluation.

The Chair of the Panel will review the membership as necessary and in conjunction with the WHSSC Medical Director and / or Director of Nursing.

For particularly complex cases the IPFR Panel may invite other individuals with clinical, pharmacy or commissioning expertise and skills, unconnected with the requesting provider to support decision making.

**** Definition: Not registered as a healthcare professional, either lay (not currently a healthcare worker) or lay plus (no healthcare experience ever) (Health Research Authority (HRA) 2014) will be eligible).**

3. PROCEDURAL ARRANGEMENTS

3.1 Quoracy:

The IPFR panel will be quorate if 4 of the 7 Health Boards representative, 1 WHSSC Clinical Director or deputy plus the Chair or Vice Chair.

3.2 Meeting Frequency

The IPFR panel will normally be held twice per month either virtually, face to face or a combination of both.

3.3 Urgent Cases

Provision will be made for occasions when a decision may be required urgently.

Where possible a virtual panel will be held to consider urgent cases. If this is not possible due to the urgency of the request or availability of panel members, then the Managing Director of Specialised and Tertiary Services with either the Medical Director or the Director of Nursing Quality and the Chair (or a Vice Chair) of the WHSSC Panel are authorised to make a decision outside of a full meeting of the Panel, within their delegated financial limits, on behalf of the Panel.

Urgent cases will be reported at the next scheduled IPFR panel.

3.4 Members Interest during the meeting

At the start of the meeting, members must declare any personal or prejudicial interests relating to the discussions of the panel.

3.5 Situations where the panel cannot reach a consensus

IPFR panel members will seek to achieve decisions by consensus where possible. If the panel is equally split the Chair of the Panel will make the final decision.

3.6 Documentation, Reporting and Monitoring:

The IPFR Co-ordinator will document the meetings to ensure panel discussions and decisions are appropriately documented.

An electronic National IPFR database of all cases will be maintained by AWTTTC.

4. TRAINING FOR IPFR PANEL MEMBERS

All Panel members will receive a local induction programme.

Panel members should have the opportunity to attend a separate annual refresher session to ensure all members maintain the appropriate skills and expertise to function effectively.

5. REVIEW OF THE TERMS OF REFERENCE

The Terms of Reference of the Panel will be reviewed in line with the All Wales IPFR Policy.

3.8.2 Appendix 2

Y Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group
Cangen Fferylliaeth a Rhagnodi
Pharmacy & Prescribing Branch



Llywodraeth Cymru
Welsh Government

Dr Sian Lewis
Managing Director
Welsh Health Specialised Services Committee

By email to: Jacqueline.evans8@wales.nhs.uk

28 July 2022

Dear Sian,

Re: WHSSC Individual Patient Funding Request (IPFR) Panel – Terms of Reference

Further to your letters of 1 April and 23 May, our meeting on 10 May, and the subsequent discussion with health board (HB) and NHS Trust Medical Directors on 1 July, this letter sets out a proposal for addressing the issues you have raised in relation to the operation of the Welsh Health Specialised Services Committee'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").

We are broadly in agreement that the current IPFR policy on the whole works well. Since introducing the policy in 2017 there has been a significant reduction in the number of IPFR requests made to NHS organisations and an increasing proportion of requests are approved. These measures indicate the IPFR policy is working for patients and their clinicians, and this is supported by the findings of the quality assurance processes put in place to support the policy.

That said, we note a request for a judicial review in the case of Maria Rose Wallpott (MW) – v- (1) WHSSC & (2) Aneurin Bevan UHB (ABUHB) was allowed and the decision of the WHSSC IPFR panel to refuse funding for treatment was quashed by the court. Subsequently, legal advice has indicated the IPFR policy is now to be interpreted in such a way that is 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.

Review of the All NHS Wales IPFR policy

We have taken the opportunity to revisit the findings of the independent review of the IPFR process and the report published by Welsh Government in 2017 which states (emphasis added):

“6. The patient’s clinical circumstances should be considered in comparison with other patients with the same condition and at the same stage in the progression of that condition.

7. The words “significantly different to the general population of patients” mean that the patient’s condition does not have substantially the same characteristics as other members of that population. For a patient to be significantly different, their particular clinical presentation was unlikely to have been considered as being part of the population for which the policy was made.”

This accords with your interpretation of the policy and strengthens the arguments for revisions to the wording of the IPFR policy to put beyond doubt how the policy should be interpreted. To that end we are content to agree a *de minimis* review of the IPFR policy subject to the conditions set out below.

- The IPFR Policy is an NHS Wales’ policy owned by each of the HBs who have statutory responsibilities in relation to IPFR decisions. The outcome of any review must therefore be agreed by each of the HBs; retaining an all-Wales approach to IPFR decisions is of primary importance given reducing variability in decision making has been a key success of the policy; and
- WHSSC is constituted as a sub-committee of all seven HBs and its Joint Committee (JC) can delegate certain activities to WHSSC directors as described in section 3.3.1 of the WHSSC Standing Orders (SO’s). On this basis, it was agreed at the All Wales Medical Directors Group (AWMDG) meeting, at which you were in attendance, that a de-minimis review with comprehensive stakeholder engagement could be taken forward by the WHSSC team. It was also agreed that this should report into WHSSC’s JC but with final approval being sought from HBs in keeping with the previous approach taken by WHSSC when making complex or contentious decisions and in keeping with WHSSC’s SOs.

Terms of Reference (ToR) of the All Wales IPFR Panel

The All Wales IPFR Panel is a sub-committee of the WHSSC JC and therefore it is within its authority to update and approve the terms of reference (ToR).

As agreed at the AWMDG meeting a process of engagement for both the de-minimis review of the Policy wording and the changes to the ToR should be undertaken with key stakeholders including the All Wales Therapeutics a 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 (VUNT).

Following the engagement process, an amended Policy and new TORs should be submitted to the JC for consideration, and then go to HBs for final approval. Finally, we would ask you share any changes, agreed with HBs, with us prior to their adoption. As we discussed we would fully support moves to appoint a remunerated chair for WHSSC’s IPFR panel and would be happy to discuss this with you in the future.

We trust the letter provides a clear outline of next steps, however if you have any queries, please do not hesitate to contact us directly.

Given the implications for HBs we are copying this letter to Chief Executives, Medical Directors, Directors of Public Health, Board Secretaries/ Directors of Corporate Governance and the AWTTTC QAG, all of whom will have an interest.

Yours sincerely



Andrew Evans
Prif Swyddog Fferyllol/ Chief Pharmaceutical
Officer



Natalie Proctor
Pennaeth y Gangen Fferylliaeth a Rhagnodi/
Head of Pharmacy & Prescribing

Cc:

Chief Executives, Health Boards
Medical Directors, Health Boards
Directors of Public Health
Board Secretaries, Health Boards
All Wales Therapeutics and Toxicology Centre IPFR Quality Assurance Group

3.8.3 Appendix 3



ROLE DESCRIPTION – CHAIR OF THE WHSSC INDIVIDUAL PATIENT FUNDING REQUEST (IPFR) PANEL v0.3

Accountable to: Chair of WHSSC

Appointment: Chair of WHSSC

Term of office: The Chair of the WHSSC IPR Panel will be appointed for a period of up to 3 years and will be subject to an annual review by the Chair of WHSSC. They may be re-appointed for a further period of up to 1 year but may not serve longer than 4 years in aggregate.

Time commitment: Approximately three days per month.

Remuneration: £160 per day

Liaison with: Members of the of the Corporate Directors Group, Officers of WHSSC, Members of the WHSSC IPFR Panel, Members of the Joint Committee, Local Health Boards, Llais and key stakeholders within the community.

1. Role of the Individual Funding Request Panel

The IPFR Panel work to the published All Wales IPFR Policy, Making decisions on Individual Patient Funding Requests.

Add link when revised policy is published

The Panel acts as a subcommittee of the WHSSC Joint Committee and hold delegated Joint Committee authority to consider and make decisions on requests to fund healthcare for patients who fall outside the range of services and treatments that WHSSC has agreed to fund routinely.

2. The role of the Chair

The Chair has a responsibility to:

- ensure that the panel works within the process set out in the All Wales IPFR Policy and the WHSSC IPFR Panel Terms of Reference;
- ensure the panel apply the process consistently and equitably;

- provide leadership to the panel in working to gain a consensus decision, or if a consensus is not met, to make the final decision;
- prepare thoroughly for each panel meeting, reading and digesting papers in advance of the meeting;
- chair the IPFR panel ensuring
 - i. a balance is struck between time keeping and space for discussion
 - ii. business is dealt with and outcomes and any actions agreed
- facilitates contributions from members, ensuring equity among panel members;
- keeps up to date on developments in the IPFR process;
- co-ordinates a regular review of the effectiveness and impact of the panel, including input into the preparation of reports where required;
- review the membership of the Panel as necessary (in conjunction with the WHSSC Medical Director and/or Director of Nursing);

3. Induction and refresher skills

It is essential that the Chair become conversant at the earliest opportunity with the WHSSC IPFR Panel activities, its strategy and the main areas of risk.

The Chair should:

- Participate in the induction programme including meeting Corporate Directors, attending briefings, meetings and reading induction materials;
- Familiarise themselves with the key challenges and areas of risk facing the panel and Specialised Services; and
- Take opportunities to develop and refresh their knowledge and skills and ensure that they are well informed in respect of the main areas of WHSSC activity.

4. Time commitment

Prior to taking the appointment successful candidates should confirm to the WHSSC Chair that they have sufficient available time to discharge their responsibilities effectively. Once appointed the IPFR Panel Chair should inform the Chair of WHSSC of any changes to their time commitments that are likely to impact on their ability to discharge their responsibilities effectively.

5. Person specification

5.1 Qualities required for the role of the Chair

To be considered, you must be able to demonstrate that you have the qualities, skills and experience to meet all the essential criteria for appointment. The work of the IPFR panel is sensitive in nature and the Chair should be analytical, articulate and able to carry authority, as well as being well equipped to deal with the challenges of working with emotive issues. The IPFR panel can be involved in making difficult decisions regarding the availability of services to patients and as such, the Chair should be experienced at managing debate.

5.2 Public Interest & accountability

The Chair should have:

- strong commitment to maintain a patient focus in the commission of health services;
- high level of understanding and interest in specialised health services issues, NHS Wales and the wider environment in which it operates
- wiliness to maintain and uphold accountability;
- a clear understanding and commitment to the principles of Nolan's Seven Principles of Public Life and
- a clear understanding and commitment to equality issues and challenging discriminatory practices;

5.3 Knowledge & Experience

The Chair should:

- have experience of working in committees and have the ability to chair meetings or the capacity and desire to take up training to become an effective Chair;
- have the ability to listen, reflect and challenge; and
- have a good level of understanding and interest in Specialised Services.

5.3 Personal Attributes and Skills

WHSSC has defined a set of shared core values:



To show your commitment to these values you will need to be able to demonstrate the following:-

- strong interpersonal skills with personal impact and credibility to be an effective advocate and ambassador with strong influencing and negotiating skills;
- excellent communication skills, with the ability to be clear and succinct and to facilitate understanding of complex issues while demonstrating respect for the views of others;
- sound judgement, sensitivity and political awareness;
- capacity to be independent and resilient;
- have the ability to think clearly and exercise sound judgment;
- have the ability to work collaboratively to work positively and operate as part of a team;
- have the ability to project and promote a confident, energetic and resilient attitude at all times, providing appropriate challenge where necessary;
- have demonstrable high level analytical skills;
- have highly sophisticated political awareness, subtlety, tact and absolute discretion;
- have sound knowledge of corporate governance; and
- have sufficient time and commitment to fulfil the role.

Welsh language skills are desirable. All candidates will be expected to display empathy towards the language and demonstrate leadership to strengthen bilingual service provision within the NHS in Wales.

3.8.4 Appendix 4



ROLE DESCRIPTION –LAY MEMBER OF THE WHSSC INDIVIDUAL PATIENT FUNDING REQUEST (IPFR) PANEL 0.4

Accountable to: Chair of the WHSSC IPFR Panel

Appointment: Chair of the WHSSC IPFR Panel

Term of office: The Lay Member of the WHSSC IPR Panel will be appointed for a period of up to 3 years. They may be re-appointed for a further period of up to 1 year but may not serve longer than 4 years in aggregate.

Time commitment: Approximately two days per month.

Remuneration: £90 per full day

Liaison with: Members of the of the Corporate Directors Group, Officers of WHSSC, Members of the WHSSC IPFR Panel, Members of the Joint Committee, Local Health Boards, Llais and key stakeholders within the community.

1. Role of the Individual Funding Request Panel

The IPFR Panel work to the published All Wales IPFR Policy, Making decisions on Individual Patient Funding Requests.

Add link when revised policy is published

The Panel acts as a subcommittee of the WHSSC Joint Committee (JC) hold delegated JC authority to consider and make decisions on requests to fund healthcare for patients who fall outside the range of services, and treatments that WHSSC has agreed to fund routinely.

2. The role of the Lay Member

Lay members are members of the public who may also be patients or carers.

Lay member representation brings important views and perspectives into the IPFR Panel decision making. It is important to ensure that decisions are made with patients at the heart of the process.

This role is to:

- Provide a key role to support decision making on individual patient treatment funding through following the All Wales IPFR Policy.
- Support consensual decision making in the context of equity and fairness for the population of Wales for which WHSSC is the responsible commissioner.
- Use skills and experience as members of the public to bring independent judgement and experience from a lay perspective and apply this to the benefit of the IPFR decision making.

3. Main Duties

- Receive anonymised and appropriately redacted application forms and copies of any additional correspondence or reports which may be relevant to an individual case prior to each meeting. This will be done electronically.
- Undertake appropriate preparation ahead of IPFR Panel meetings by fully reading and appraising the documentation that supports each case.
- Participate effectively in IPFR Panel meetings to help to ensure that the decisions and recommendations of the IPFR Panel are reached by consensus based on the information, clinical evidence and any requested expert clinical advice provided to it.
- Actively participate in discussions so that a full discussion about each case takes place, enabling a balance between the needs of the individual and equity and fairness for the population.
- Engage positively and collaboratively in the discussion of all individual cases, providing an effective contribution.
- Ensure the Chair is aware of any declarations of interest ahead of any case discussion
- Participate in the annual IPFR training sessions.

4. Person specification

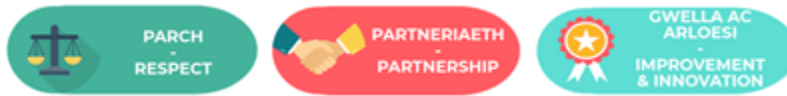
4.1 Knowledge & Experience

Experience of working in committee setting.

It is also desirable to have experience of working in the NHS or other public sector organisation and experience of working in the NHS or other public sector organisation.

4.2 Personal Attributes and Skills

WHSSC has defined a set of shared core values:



To show commitment you should demonstrate an:

- Ability to work within a defined process, applying agreed criteria consistently and equitably
- Ability to commit to attend meetings (Face to face or virtual) and adequately prepare for meetings
- Ability to bring a professional and patient centred approach to the Panel
- Ability to analysis complex information
- Ability to display objectivity and understand the need for confidentiality
- Ability to give an independent view on matters relating to the patient and public perspective of funding healthcare treatments and be articulate and able to constructively put their view across to other Panel members
- Have knowledge and understanding of equity and diversity and commitment to applying these principles

Welsh language skills are desirable. All candidates will be expected to display empathy towards the language and demonstrate leadership to strengthen bilingual service provision within the NHS in Wales.

4.2 Other

- Not currently an NHS employee
- Willingness to undertake the necessary training