



AWTTC

All Wales Therapeutics & Toxicology Centre
Canolfan Therapiwteg a Thocsicoleg Cymru Gyfan

Individual Patient Funding Request (IPFR) Quality Assurance (QA) Group Audit

11th November 1.30pm via Teams

Meeting minutes

Present:

Group members	Observers
Professor James Coulson (Director, AWTTC) Chair	Mrs Gail Woodland, AWTTC
Dr Michael Thomas (Consultant in Public Health Medicine, HDUHB)	Ms Rosie Spears, AWTTC
Mrs Ann-Marie Matthews (lead IPFR co-ordinator)	Miss Laura Phillips, AWTTC
Ms Rebecca Boyce (Health Technology Wales representative)	Miss Jessica Clements, Medical Student, Cardiff University
Mrs Pam James (Lay representative)	
Mrs Fiona Woods (Lay representative)	

The meeting started at 1.30 pm

Introduction: Members were welcomed by the Chair who introduced Miss Jessica Clements, medical student at Cardiff University. He asked the group if there were any objections to her observing the meeting, there were none. Members were asked to declare any interests. Interests were declared by Ann-Marie Matthews for Aneurin Bevan University Health Board and Dr Michael Thomas for Hywel Dda University Health Board and for the Joint Commissioning Committee (JCC); both members were asked to leave the meeting during discussions for these respective cases. Applications from the period July to September 2024, one from each panel, were considered at the meeting against the criteria shown in Table 1.

There was no feedback to report from panels

Table 1. Criteria used for IPFR quality assessment audit

Process	Evidence to assess whether the process has been adhered to	Criteria
Application process	IPFR application form, clinic letters/associated	Was this an appropriate request to consider via the IPFR route?
		Was the IPFR application form signed?

	emails and IPFR panel minutes	Was there sufficient information provided for the case to proceed to panel?
	Date of receipt of IPFR versus date of IPFR meeting versus urgency ticked	Was the case taken to panel within the timescale stipulated on the application form?
Panel process	IPFR panel minutes	Was the panel quorate?
		Was the discussion held by the panel in line with the decision-making guide?
		Was the decision and rationale for the decision clearly described in the minutes?
Decision process	IPFR panel minutes, IPFR decision letter to clinician, IPFR decision letter to patient, date on letter vs. date of meeting	Did the letter to the clinician clearly state the decision and explain the reason for the decision?
		Was the decision letter sent to the clinician within 5 working days of the panel's decision?
		Did the letter to the clinician state the review deadline date, and enclose the review form and guidance notes where applicable?
		Was the letter to the patient sent within 5 working days of the panel's decision?

IPFR cases:

The Group went through each panel IPFR application in randomised order. The Group looked at each criterion in turn and were asked as to whether the criterion was met, not met, undecided or not applicable. For any criterion that wasn't met the Group provided reasons for their opinion. The group were also encouraged to make general comments which could be shared across all panels, in particular examples of good practice and any common themes highlighted by this audit process.

The Group were pleased to note that five of the eight panels met all of the criteria. All panels were quorate or used Chair's action appropriately for urgent cases. All applications were appropriate to be considered via the IPFR route.

The QA Group considered that sufficient information was provided in the submission for the case to go to panel in seven cases. In one case it was noted that treatment had already commenced, however no information had been provided on the patient's response to treatment. The group noted that a

couple of the application forms had been particularly well completed. There were some good examples of medicine evidence summaries provided the relevant health board pharmacist for some of the applications considered at panel. The group encourage these summaries to be redacted of any confidential information and uploaded to the evidence section of the All Wales IPFR database for the benefit of other users of the database.

All but one of the cases assessed met the urgency timelines requested on the form. In one case there was significant delay whilst the panel decided if it was a suitable case to be considered via the IPFR process. Although the case was requested as non-urgent, several months elapsed between the submission of the request and the final panel decision. For all requests considered by panels in the quarter July to September 2024, only two panels met the urgency requested in 100% of cases. One panel did not report the urgency and the other five met urgency in between 75% and 88% of the cases for the quarter.

The Group felt that the majority of panel discussions were in line with the decision-making guide. However, for one case that fell outside of policy the panel did not follow the decision-making guide criterion. The group felt that decision making criteria could still have been followed and ethical considerations would have facilitated a panel decision. The approach to assessing part 9B of the application form was also questioned, under the 2017 policy, panels are expected to consider significant clinical benefit compared with others with the same condition at the same stage. Further changes are being made to the revised IPFR Policy and it is the understanding of the QA group that health board panels are awaiting these changes and subsequent health board sign off before implementing the new policy. In one case the panel had considered significant benefit to the patient over other treatments but not compared to the same cohort of patients. The panel report will include a reminder that it is the understanding of the QA group that this change has not yet been formerly adopted by health boards in Wales. This would otherwise result in an inconsistency in approach across Wales.

The group noted that in a couple of cases the term exceptionality was still being used; panels will be reminded of the accepted terminology as per the current IPFR Policy. The group still feel that economic considerations are, in general, limited. Although it is accepted that cost effectiveness information is unlikely to be available, consideration of associated or offset costs should be possible in the majority of cases to provide value for money judgements. If there are no offset costs then this should also be acknowledged by the panels.

In all of the cases the panel meeting minutes were judged to represent the discussion and described the decision and rationale adequately. However, in one case the group felt that the minutes could have provided more detail. In two cases the minutes had not been signed by the panel Chair, although in one of these cases this was explained to be unavoidable due to absence.

The QA Group also thought that one panel provided too much detail in the letter to the clinician by including the full decision record. As this application was approved, the level of detail was not necessary and could have been more concise. One of the letters was not signed by the panel Chair.

In two cases the letter to the clinician was sent outside of the five-day deadline. In one case the patient letter fell outside of the five-day deadline by one day, in the other the letter was sent eight days after the panel date although the clinician had been emailed on the day. In two cases the patients were hospital in-patients and so no patient letter was required.

IPFR panel attendance

Ann-Marie Matthews reported back to the group on the Powys THB panel meeting she attended on 15 October 2024. One IPFR application was considered at the meeting. The request was appropriate and panel was quorate including two lay members. Ann-Marie noted that there was an evidence summary provided by the pharmacy department included in the supporting paperwork. Ann-Marie commented on the detailed clinical discussion and in particular on the comprehensive economic considerations including discussion of opportunity costs. The panel also discussed what would be the effect on the patient if the request was not approved. Overall Ann-Marie described a detailed discussion which followed the decision-making guide in the IPFR Policy.

Policy update

Ann Marie Matthews informed the group that there have been no changes to the policy as yet. James Coulson and Ann-Marie attended a meeting with NHS Wales Joint Commissioning Committee (NWJCC) in September to discuss changes to part 9 of the application form to provide clarity as to how panels should consider the information provided in this section. NWJCC will be taking these changes in addition to an update of the Terms of Reference for the NWJCC IPFR panel. Legal advice will be sought to ensure changes are acceptable before circulating to health boards in Wales for discussion and ratification. The group are informed that NWJCC are still using the updated policy whilst health board panels are using the existing policy. If no progress is reported before the February 2025 QA meeting the IPFR QA Chair will write to NWJCC for an update.

Post meeting note. The policy has since been updated and sent to those who had attended the consultation meeting in September.

AOB

None raised

Future IPFR QA meetings

The next IPFR QA meeting is 3 February 2025 at 1.30-3.30 pm

The Chair closed the meeting at 3.30 pm.