

Reporting Committee	JCC - All Wales Individual Patient Funding Request (IPFR) Panel
Chaired by	Elizabeth Abderrahim
Lead Executive Director	Professor Iolo Doull, Medical Director
Date of last meeting	All Wales IPFR Panel meeting 18 June 2025

Summary of key matters considered by the Committee and any related decisions made.

The following table demonstrates the number of requests considered at the Chair's Action Panel meetings and All Wales IPFR Panel meetings during this reporting period.

	Number of Requests discussed as Chair's Actions	Number of Requests discussed by WHSSC IPFR Panel
May	2	11
June	1	8

Key risks and issues/matters of concern and any mitigating actions

Health Board Attendance progress

There are no concerns to escalate during this reporting period.

Vice Chair Vacancies

Concerns have been raised that the All Wales Individual Patient Funding Request (IPFR) Panel still remains without a Vice Chair and there is a risk that meetings will not be able to be held should the Chair become unavailable.

Discussions are taking place to determine the appropriateness of one of the NWJCC Panel members taking on the Vice Chair role. Current HB Panel Members have indicated that they are unable to support the role due to time commitments.

Lay Member Vacancies

Sadly, our long-standing Lay member, Professor Sheila Hunt, has now resigned from her role as Lay Member on the All Wales IPFR Panel. This means that the Panel now stands with no Lay Member representation which is a concern.

NWJCC are currently in the process of advertising the posts on TRAC but there have been a number of delays which are being addressed. A further update will be provided in the next report.

Individual Patient Funding Request (IPFR) Quality Assurance (QA) Group Audit Report – May 2025

One of the roles of this group is to consider an anonymised random sample of IPFR reports (one from each IPFR panel in Wales) in relation to their completeness, timeliness and efficiency of communication in line with the NHS Wales IPFR policy process. The full terms of reference of the group are available on the All Wales Therapeutics and Toxicology Centre website. During this meeting the group considered one application from each panel considered between January and March 2025.

The report highlighted that nine of the ten criteria assessed were met for the IPFR assessed from the JCC.

The QA group did not think that the application had included sufficient information to proceed to panel as there was no information on how the patient differed with others with the same condition and there was no economic information provided. The panel noted that the patient did not meet the NWJCC commissioning criteria and could not see any evidence as to why the patient was different to others who did not meet the criteria. The panel therefore did not consider the clinical, cost or ethical criteria. The QA group therefore decided that they could not assess the decision-making discussion.

The Group noted the clear decision record which stated that the IPFR Policy decision-making guide had been used and the panel had considered the request under part 9A of the form.

In the quarter January to March 87% of requests considered by NWJCC met the urgency stipulated. This is similar to the previous quarter (86%) and an improvement on the same quarter in 2024 when 69% of requests met urgency. No additional redactions were required to the paperwork prior to sending to Group members.

The Group have noted in general an improvement in the quality of completed forms and documentation provided, especially with the inclusion of offset costs in the economic sections of some of the forms. For one urgent request the Chair and the Vice Chair of the panel were not available. The IPFR coordinator was commended on escalating the request to the Health Board Medical Director to ensure that the urgency was met. This was considered good practice to be shared across the teams.

Matters referred to other Committees

- None

Confirmed Minutes for each of the meetings are available on request.

Date of next meeting

16 July 2025