



AWTTC

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



Individual Patient Funding Request (IPFR)

Annual Report 2024-2025



*This document is available in Welsh
Mae'r ddogfen hon ar gael yn Gymraeg*

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AWTTC Clinical director's statement

2024-2025 has been a year of collaboration and stakeholder engagement. Focusing on the need to provide a transparent, inclusive and patient-focussed approach to funding decisions in Wales.



Prof James Coulson
Clinical Director, AWTTC

The number of IPFR cases considered across panels continues to rise, due to an increase in medicines requests this year, which rose by 7% during 2024 to 2025 compared to 2023 to 2024. Whilst medicines-related requests continue to rise this is not the same for non-medicine related requests. The NHS Wales Joint Commissioning Committee (NWJCC) has the highest number of non-medicines IPFR requests by far, but this was lower than the previous year and drove the reduction in overall requests. This might be due to changes in commissioning arrangements and policy updates, but it was interesting to see that there was a reduction in the number of surgical procedure requests alongside a drop in requests for cytoreductive surgery and hyperthermic intraperitoneal chemotherapy.

Approval rates are steadily increasing and reached 83%, higher than the 79% approval rate reached last year. Alongside an improvement in approval rates, we saw progress in the number of outcomes reported to IPFR panels for approved treatments. More importantly, patients are doing well on treatment, with higher response rates (79%) and better quality of life than reported previously.

We plan to undertake an online workshop in the latter half of 2025. This will be advertised through the All Wales Therapeutics and Toxicology Centre (AWTTC), and all content will be provided on the IPFR pages of the AWTTC website.

At the time of writing this statement, the updated IPFR policy is being taken through health board committees for sign-off. This is fantastic news. Led by NWJCC, this collaborative effort involves the NHS Wales IPFR Policy Implementation Group, IPFR Chairs, IPFR Quality Assurance Group and AWTTC. It is vital that IPFR panels are working to the same policy to ensure consistency in decision-making for patients and clarity for clinicians submitting requests. We noted that there was one independent review requested this year.

The main way in which I can assess consistency of decision-making is through my role as Chair of the IPFR Quality Assurance Group. We continue to meet every quarter to assess an

application from each IPFR panel and consider three parts of the process: application, panel and decision. Overall, panels are meeting the three process criteria assessed, but we noted an effect on panel process scores in relation to the existence of two IPFR policies being available at the same time. In particular, how part 9b applications (where there is no existing technology advice, guidance or policy) are being considered. After the sign-off of the new policy across the health boards, I expect to see an improvement in this criterion next year.

We will continue to work with panels on their consideration of value for money concepts. We will also encourage the use of local pharmacy departments and Health Technology Wales (HTW) to provide evidence reviews for medicines and non-medicines related requests, respectively.

I am encouraged by the local improvements happening across the panels. Swansea Bay University Health Board (UHB) IPFR panel are streamlining their processes to work more effectively and have undertaken an analysis of their last 5 years of IPFRs. I will be interested to see the outcomes from this review, which will support the sharing of good practice across the panels. And it is good to see that Swansea UHB are being proactive in their recruitment drive of new lay members due to current vacancies.

For information on becoming an IPFR lay member, please refer to the [AWTTC website](#). Cardiff and Vale UHB have trained new public health consultants and provided training to the local vascular network manager. Ensuring that local clinical networks are kept informed and updated on the IPFR service is valuable to enable appropriate and efficient use of the service. We are keen to support the work of Powys THB to review any differences in approach to the IPFR process between panels.

Finally, I would like to thank the NHS Wales IPFR Policy Implementation Group (PIG) for their support over the this and previous years. The PIG brings together representatives from Health Boards, the NWJCC, AWTTC, and HTW to ensure the fair and consistent application of the IPFR Policy across Wales. The Group promotes best practice and helps shape national policy. It also works to improve understanding of the IPFR process, enhance data quality, and inform future commissioning. The group promote the messaging from the IPFR QA group and the broader AWTTC role providing feedback as we make further developments to the IPFR database and inputting into the IPFR annual report. They have also contributed to the update of the IPFR policy and associated documentation and the training of panel members and clinicians through local initiatives and at the IPFR workshops.

Executive summary

- In 2024–2025 the total number of IPFRs across Wales increased to 403 from 392 in 2023–2024. There were large increases in requests for medicines, up by 7% and a drop in requests for non-medicines by 6%.
- 42% of the IPFRs were to treat cancer conditions, a fall from 52% of requests in 2023–2024. This was mainly driven by a drop in requests for medicines to treat blood cancers.
- Powys Teaching Health Board continued to have the highest rate of IPFRs per 100,000 population. This was due to the higher rate of medicines-related requests in Powys, at 14.2 per 100,000 population. Cardiff and Vale UHB had the highest rate of non-medicine requests, equating to 8.9 per 100,000 population.
- As in previous years, the NHS Wales Joint Commissioning Committee had the highest number of non-medicine IPFR requests, of which 69 (46%) were for positron emission tomography (PET) scans.
- Four health boards saw an increase in medicine-related requests. Betsi Cadwalader UHB had the highest number of medicine-related requests, up by 25% on the previous year.
- The number of IPFRs approved is steadily increasing, with 83% of all IPFRs approved compared with 79% in 2023–2024.
- The percentages of patient outcomes reported in 2024–2025 was 18.5% of all IPFRs considered, representing an increase by 4% from last year. Overall, 79% of people reported a complete or partial response to treatment, up on last year (67%); and 78% had an improvement in quality of life, also higher than last year (67%).
- Between 83% and 96% of IPFRs reviewed by the IPFR Quality Assurance group met the criteria used to assess how well panels are following the IPFR policy. This is comparable to the previous year and suggests good adherence to the IPFR policy.
- As of March 2025, there were 21 published One Wales decisions on medicines; 19 of them were positive recommendations enabling access to medicines for the treatment of patients with conditions where there is an unmet clinical need. Further detail is provided in the AWMSG annual report. This report and all One Wales decisions are on the AWTTTC website.

Background

A comprehensive range of NHS healthcare services are routinely provided across health boards in Wales. The NHS Wales Joint Commissioning Committee (NWJCC), working on behalf of the seven health boards in Wales, commissions specialised services at a national level. Each year, the health boards and NWJCC receive requests for healthcare that fall outside the range of services agreed. Individual Patient Funded Requests (IPFRs) are defined as ‘requests to a health board or NWJCC to fund NHS healthcare for individual patients whose needs fall outside the range of services and treatments that a health board has arranged to routinely provide’. The healthcare requested can include, for example, a request for a surgical device or piece of equipment, a medicine or a surgical intervention.

Further information about the IPFR service in Wales can be found on the [AWTTTC website](#).

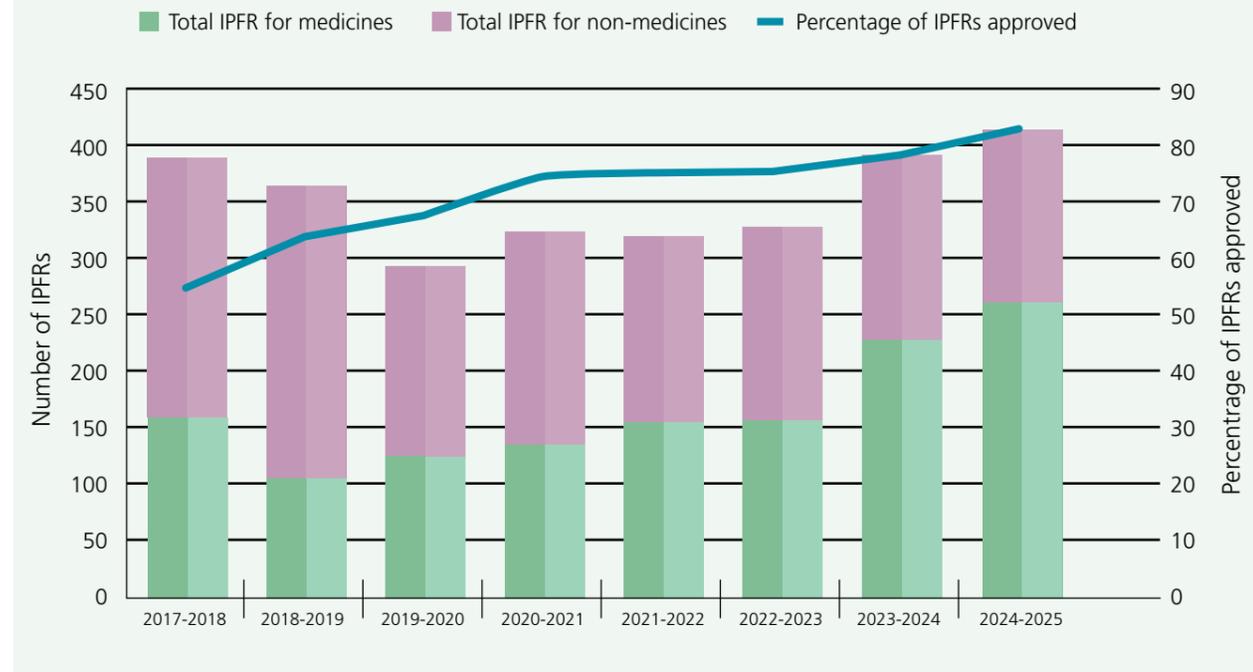
AWTTTC supports the IPFR service in Wales developing and updating the IPFR database, auditing and maintaining the quality and desired level of service, identifying cohorts and medicines for the One Wales Medicines Process, and hosting an annual workshop and training event for IPFR panel members.

Individual Patient Funding Requests

Between 1 April 2024 and 31 March 2025, panels in Wales considered a total of 403 IPFRs. This is a modest increase compared with 2023-2024 when 392 IPFRs were considered, and the highest annual total recorded in the past eight years (Figure 1).

Of the 403 IPFRs, 252 were for medicines, 150 for non-medicines and one for both a medicine and a non-medicine. In 2024-2025 the number of requests for medicines increased, and requests for non-medicines decreased slightly compared with 2023-2024. IPFRs for cancer conditions fell to 42% from 52% of requests in 2023-2024.

Figure 1: Total number of IPFRs considered in Wales from 2017-2018 to 2024-2025

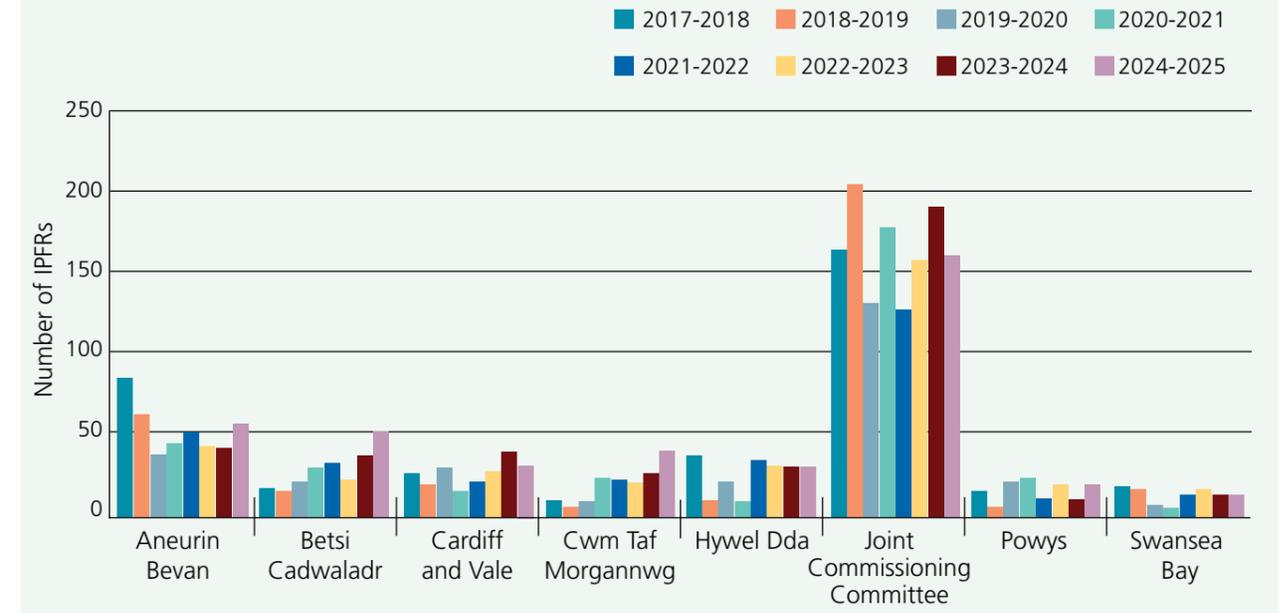


The rate of IPFRs approved has consistently increased over the years, in 2024-2025 the rate was 83%, the highest recorded.

Four of the eight IPFR panels reported notable increases in the number of IPFRs considered in 2024-2025 compared with 2023-2024 (see Figure 2). Betsi Cadwalader UHB panel reported the largest increase from 39 IPFRs in 2023-2024 to 54 in 2024-2025, representing an increase by 15 IPFRs. Aneurin Bevan UHB, Cwm Taf Morgannwg UHB and Powys Teaching Health Board (THB) reported increases in 2024-2025 of 14, 11 and 8 IPFRs, respectively. Two panels considered fewer IPFRs in 2024-2025 compared with the previous year. The NWJCC panel

reported the greatest reduction: from 189 in 2023-2024 to 160 in 2024-2025, representing 29 fewer IPFRs. Numbers for the NWJCC are now closer to those reported in 2022-2023. Cardiff and Vale UHB considered 8 fewer IPFRs in 2024-2025 than in the previous year. Swansea Bay UHB and Hywel Dda UHB considered the same number of IPFRs in 2024-2025 as in 2023-2024.

Figure 2: Number of IPFRs within each health board in Wales, including the Joint Commissioning Committee, from 2017-2018 to 2024-2025

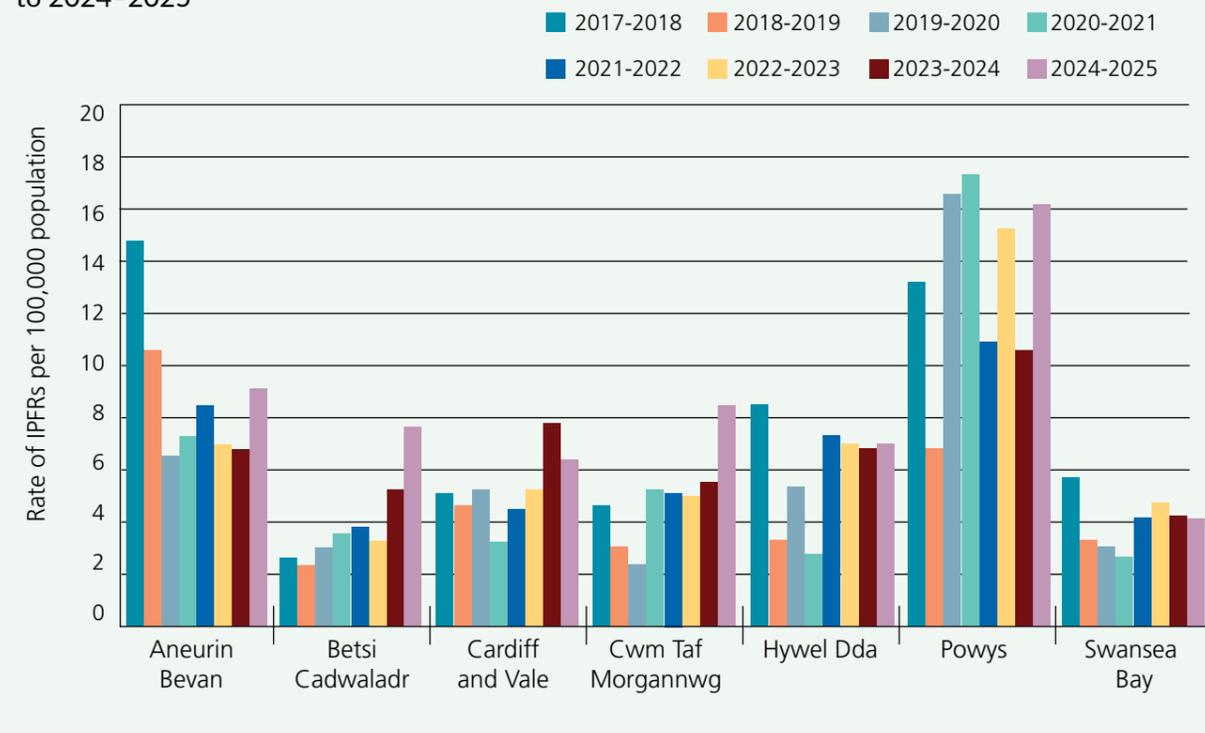


The rate of IPFRs considered by health board panels are shown in Figure 3 and have decreased and increased in line with the changes in the numbers of IPFRs considered. This is to be expected as the populations of the health boards have not changed significantly between 2023-2024 and 2024-2025. As in previous years Powys THB considered the most IPFRs per 100,000 population. Powys THB commissions services from English and Welsh providers, which results in a higher rate per population compared with the other health board panels.

During 2024-2025 the percentage of IPFRs approved by each health board and NWJCC ranged from 72% in Cardiff and Vale UHB to 91% in Aneurin Bevan UHB (Figure 4). Four health boards and NWJCC approved more than 80% of the IPFRs considered in 2024-2025. Differences in the quality and appropriateness of requests affects the approval rate, with poorly completed or incomplete forms leading to deferral of a decision or to a negative decision. Although direct comparison of approval rates between panels is problematic due to the low numbers of IPFRs

considered by some of the panels, it is reassuring to note that no significant difference in approval rates was found between panels ($p = 0.43$).

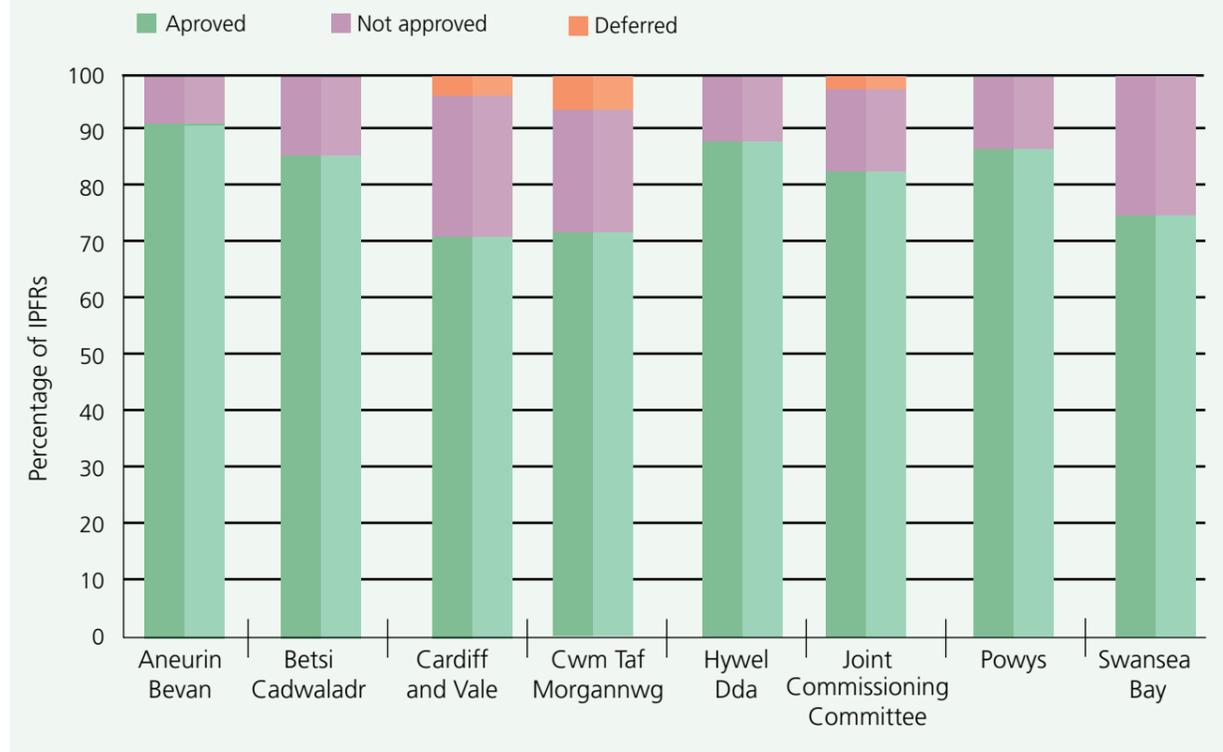
Figure 3: Rate of IPFRs per 100,000 population for each health board in Wales from 2017–2018 to 2024–2025



Continued funding

Continued funding requests are for treatments that had previously been approved for a limited time and people need to continue taking them. The applicant clinician is expected to provide evidence to the panel that the treatment is providing clinical benefit for the patient, often using pre-agreed measures. In 2024–2025, 48 requests for continued funding were considered by panels, an increase from 41 in the previous year. Of the 48 requests in 2024–2025; 44 requests were for medicines, one was for a combination of medicine and non-medicine and three were for non-medicine interventions. Powys THB considered most requests for continued funding (47%), most likely due to the high level of commissioned services from providers in England and Wales. Although this is a smaller proportion than in 2023–2024, when Powys THB considered 60% of all continued funding requests. As in previous years, all continued funding requests in 2023–24 were approved.

Figure 4: Percentage of IPFRs approved and not approved within each health board and NWJCC in 2024–2025



Independent reviews

For IPFRs that are reviewed but not recommended by the panel, the patient and their clinician may ask for an independent review of the IPFR process if they feel that the IPFR process has not been followed according to the IPFR policy. An independent review may be requested based on one or more of three grounds, as specified in the NHS Wales IPFR Policy. The three grounds are:

- **Ground One:** The health board or NWJCC has failed to act fairly and in accordance with the All Wales Policy on Making Decisions on Individual Patient Funding Requests.
- **Ground Two:** The health board or NWJCC has prepared a decision which is irrational in the light of the evidence submitted.
- **Ground Three:** The health board or NWJCC has not exercised its powers correctly.

In 2024–2025 there was one request for a review under Ground Two. Unfortunately, the patient involved passed away before the review could be considered and the review panel was stood down.

IPFRs for medicines by health board and NHS Wales Joint Commissioning Committee

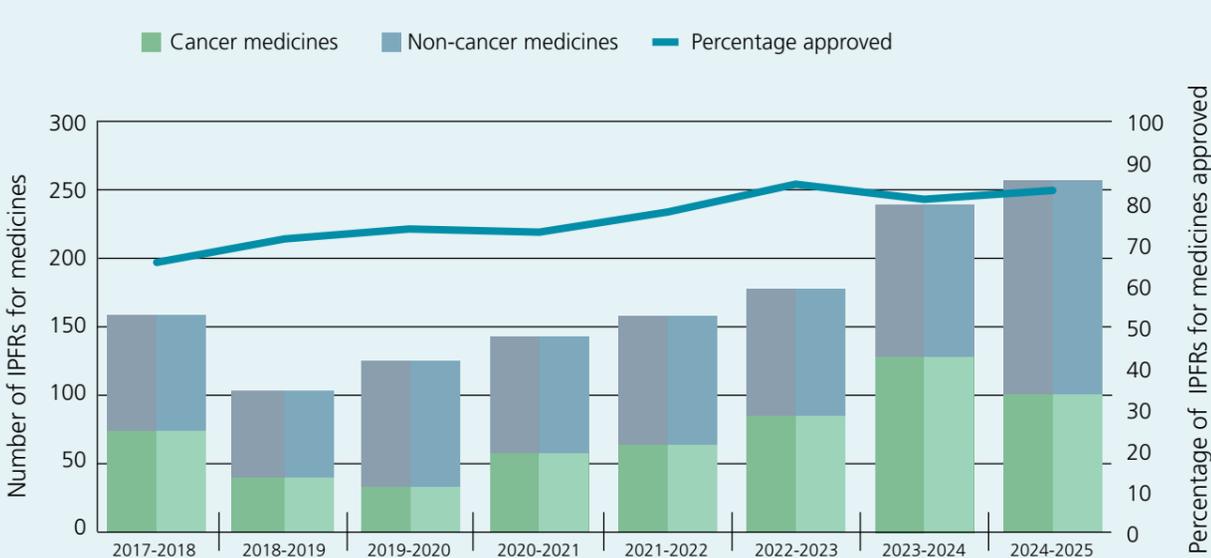
During 2024–2025 the number of IPFRs for medicines increased to 253 IPFRs from 234 in the previous year (see Figure 5). This represents an increase in medicine requests for the sixth year running.

IPFRs for use of a medicine in Wales happen for three main reasons:

- Advice in relation to a licensed indication for that medicine is not available from the All Wales Medicines Strategy Group (AWMSG) or the National Institute for Health and Care Excellence (NICE).
- AWMSG or NICE has given advice and has not recommended the medicine or is unable to recommend it.
- The medicine is being used 'off-label', that is: used outside the terms of the medicine's marketing authorisation (product licence) and there is no One Wales Medicines advice available.

Of the 253 medicine IPFRs, 211 were approved, 39 were not approved and 3 had the decision deferred. The approval rate for medicine IPFRs increased slightly to 83% in 2024–2025, from 81% the previous year.

Figure 5: Number of IPFRs for medicines considered in Wales from 2017–2018 to 2024–2025 and the percentage approved

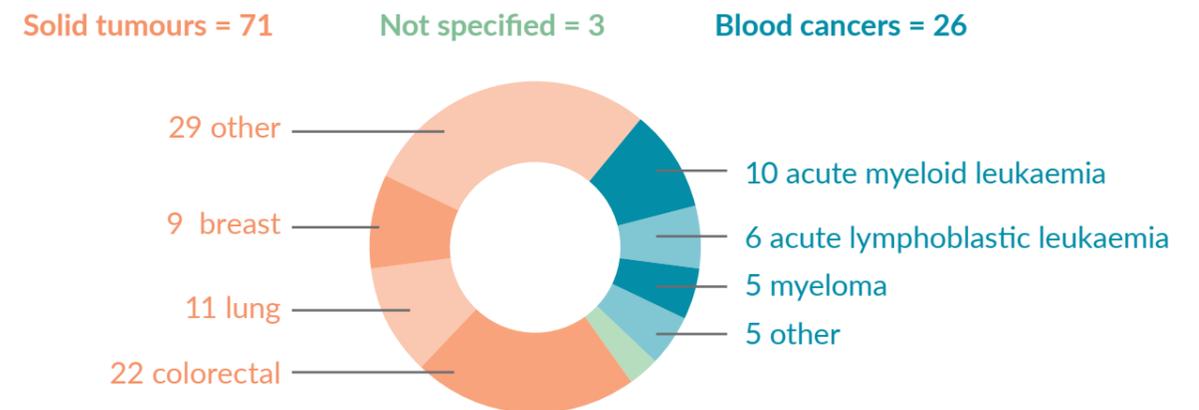


The mean annual number of IPFRs for medicines per health board in 2024–2025 was 36, representing a marked increase from 26 in 2023–2024. Mean medicine IPFRs per health board have increased since a low of 11 in 2018–2019. There is no single factor that accounts for this rise in medicine requests.

In 2024–2025 the number of IPFRs for medicines to treat cancer was 100, representing a fall from 127 in the previous year (see Figure 5). This fall was mainly driven by a fall in requests for medicines to treat blood cancers: from 47 in 2023–2024 to 26 in 2024–2025.

IPFRs for medicines to treat conditions other than cancer increased by 43% since the previous year: rising from 107 in 2023–2024 to 153 in 2024–2025. Overall, 40% of medicine IPFRs were for cancer treatments and 60% for non cancer treatments.

Medicine requests to treat cancer conditions = 100



Of the IPFRs for medicines to treat cancer there were four stand out cohorts. As was the case in 2023–2024, the most requested medicine was for trifluridine-tipiracil in combination with bevacizumab for the treatment of metastatic colorectal cancer, with 13 requests. All requests were made before the publication of [NICE TA1008](#): trifluridine-tipiracil with bevacizumab for treating metastatic colorectal cancer after 2 systemic treatments. This positive NICE recommendation was published in September 2024, after which no further requests were recorded. We expect no further requests for this medicine combination and indication.

Throughout 2024–2025 there were 8 requests for trastuzumab deruxtecan for the treatment of breast cancer. Seven of these requests were for the treatment of HER2-low metastatic or unresectable breast cancer; in July 2024 NICE published a negative recommendation for trastuzumab deruxtecan in this indication. IPFRs considered before the publication of NICE

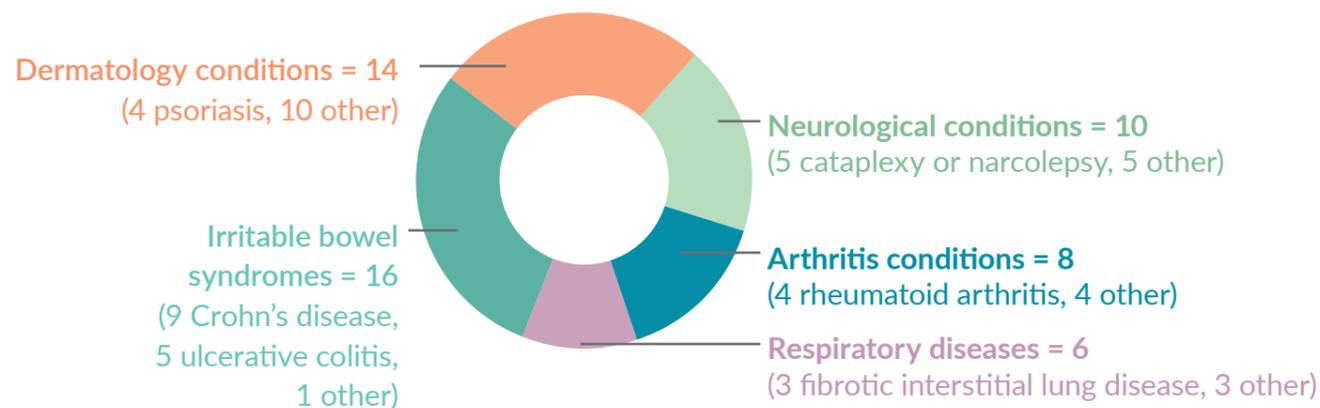
guidance were approved; no requests were approved after the publication of the negative NICE guidance.

As in the previous year, there was a notable number (7) of IPFRs for the combination of venetoclax and azacitidine for the treatment of relapsed or refractory acute myeloid leukaemia. This medicine combination is not licensed to treat this specific condition; in 2024–2025 it was flagged as a cohort to the AWTTTC One Wales (OW) medicines assessment team to consider providing all Wales advice. There were also 5 IPFRs for blinatumomab for the treatment of B-cell precursor acute lymphoblastic leukaemia in children; this has also been referred to the OW medicines assessment team for all Wales consideration.

In 2024–2025 the One Wales Medicines Assessment Group (OWMAG) considered 4 new assessments: 3 were approved and 1 was not supported for use. OW process activity for 2024–2025 is detailed in the [AWMSG annual report](#). Monitoring of IPFR data for medicine requests shows that IPFRs have not been submitted for that medicine and condition after the publication of One Wales advice. As of March 2025, there were 21 published OW decisions, of which 19 were positive recommendations. More information on the OW medicines process and current OW decisions is on the [AWTTC website](#).

In 2024–2025 medicine requests for non-cancer conditions were markedly higher than those for cancer conditions. In previous years medicine requests for non-cancer conditions have exceeded those for cancer conditions (153 and 100 requests respectively), except for 2023–2024 when a higher number of requests for cancer medicines was recorded. As in previous years the non-cancer conditions were diverse, with few cohorts identified. As in the previous year, there were 5 IPFRs for ruxolitinib for the treatment of graft versus host disease in children, which were all considered by the NWJCC panel.

Non-cancer conditions with the most requests = 54



Irritable bowel syndromes, including Crohn's disease and ulcerative colitis, were the most common non-cancer disease area for which medicines were requested. Dermatological conditions and neurological conditions also featured in the most requested non-cancer conditions.

In 2024–2025 the most common classes of medicines requested were monoclonal antibodies and tyrosine kinase inhibitors, as in the previous year. These two classes contain numerous medicines used to treat a variety of cancer and non cancer conditions. In 2024–2025 there were 8 more medicines requested in the monoclonal antibody class than in the previous year. Every year several new monoclonal antibodies are approved and their use in general is anticipated to continue increasing.

Most common classes of medicines requested:

Monoclonal antibodies



Tyrosine kinase inhibitors;



Figure 6 shows the number of IPFRs for medicines by health boards and NWJCC over the past eight years. In 2024–2025 Betsi Cadwaladr UHB had the highest number (51 requests), followed by NWJCC and Aneurin Bevan UHB with 42 and 41, respectively.

Betsi Cadwaladr UHB reported the largest increase in IPFRs for medicines during 2024–2025 with 13 more considered than during 2023–2024. There was no single medicine identified that accounted for this rise. 2024–2025 is the second year that requests for medicines have increased in Betsi Cadwaladr UHB; in 2023–2024 IPFRs increased by 15 since 2022–2023. Aneurin Bevan UHB, Cwm Taf Morgannwg UHB, Hywel Dda UHB and Powys THB all reported more modest increases of between 4 and 7 IPFRs in 2024–2025. Requests for medicines fell for NWJCC, Cardiff and Vale UHB and Swansea Bay UHB, by 8, 6 and 2, respectively. NWJCC had previously reported a large increase of 30 IPFRs in 2023–2024 since 2022–2023.

Figure 6: Number of IPFRs for medicines within each health board in Wales, including NWJCC, from 2017–2018 to 2024–2025

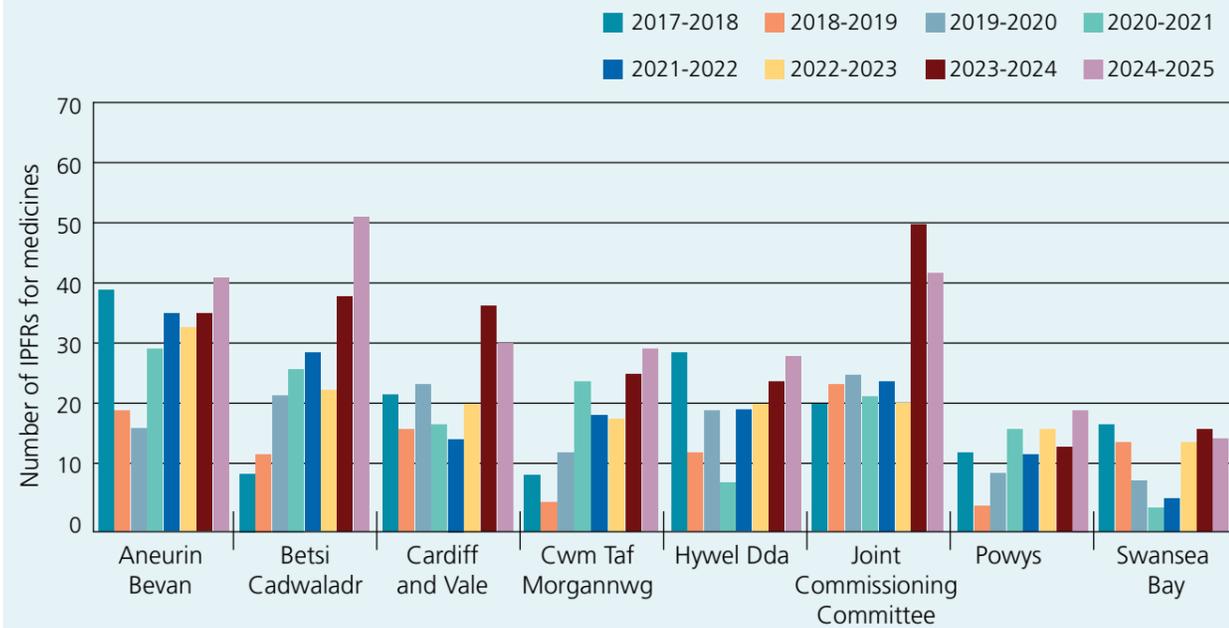
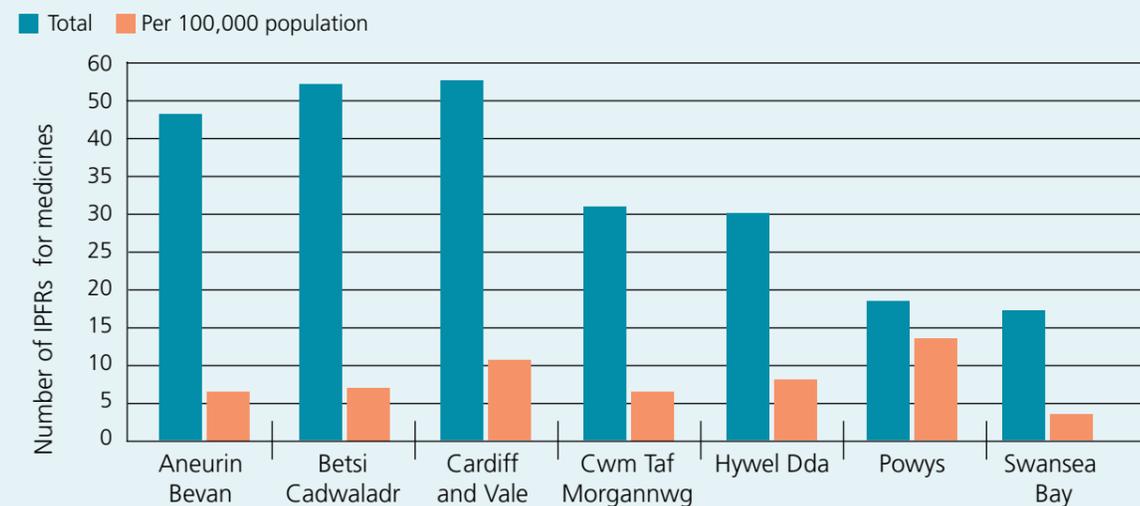


Figure 7 shows the rates of IPFRs for medicines per 100,000 population for each health board in Wales during 2024–2025. IPFRs considered by the NWJCC panel have been added to the local panel IPFRs for each health board. The rate per 100,000 population ranged from 4.4 in Swansea Bay UHB to 14.2 in Powys THB.

Differences in the rates of medicine IPFRs between health boards are not unexpected and are reported each year. The IPFR screening process can vary between health boards and some health boards have cost thresholds below which medicines are not considered through the IPFR process. For example, Powys THB consistently has the highest rate of IPFRs for medicines per 100,000 population. This is an expected finding because of known differences in process, including the absence of a cost threshold for the consideration of medicine related IPFRs in Powys THB, for other Health boards consideration of medicines below a cost threshold would be considered through non-formulary requests. Additionally, off-label or unlicensed medicines are all considered through IPFR in Powys THB, whereas other health boards may utilise different systems such as local unlicensed medicines policies for unlicensed treatments.

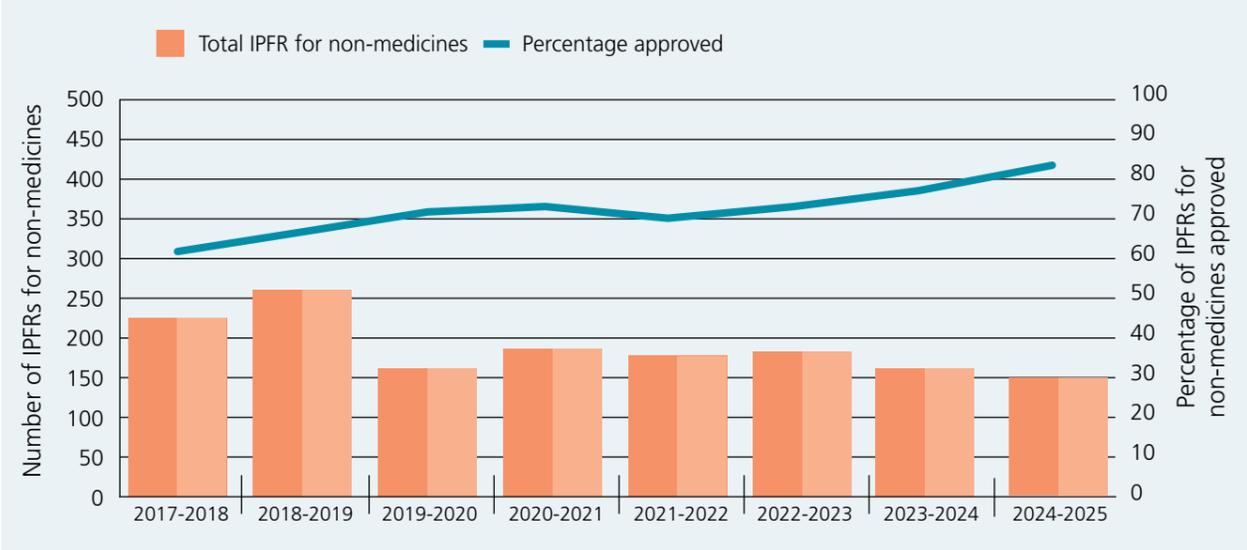
Figure 7: Number of IPFRs for medicines and per 100,000 population within each health board in Wales in 2024/2025



IPFRs for non-medicines by health board and NHS Wales Joint Commissioning Committee

The number of IPFRs for non-medicines decreased slightly from 159 in 2023–2024 to 150 in 2024–2025. The approval rate for non-medicine IPFRs increased from 77% to 81% with 122 approved, 26 not approved and 3 deferred (Figure 8).

Figure 8: Number of IPFRs for non-medicines and percentage approved between 2017–2018 to 2024–2025



After a high of 258 non-medicine IPFRs considered by panels in Wales in 2018–2019 the annual total has fluctuated between 150 and 190 since 2019–2020. In 2024–2025 there were 150 non-medicine IPFRs considered by panels in Wales, a slight decrease since the previous year and the lowest number since we started reporting in 2015–2016 when 374 non-medicine IPFRs were considered by panels in Wales (not shown on graph).

In 2024–2025 the overall upward trend in the approval rate continued, with a rate of 81%, the highest rate reported since 2015–2016 (60% approved). A continued improvement in the quality of applications and supporting information as well as a better awareness of appropriate routes for accessing treatments may contribute to the higher percentages of IPFRs approved.

As in previous years most (79%) non-medicine IPFRs in 2024–2025 were considered by the NWJCC panel with 118 (Figure 9). The health board panels considered few non-medicine IPFRs, ranging from 0 for Hywel Dda UHB to 14 for Aneurin Bevan UHB. This represented an increase from 7 in 2023–2024 to 14 in 2024–2025 for Aneurin Bevan UHB. For the other health boards the numbers of non-medicine IPFRs were low and changed little compared to the previous year.

Figure 9: Number of IPFRs for non-medicines within each health board in Wales, including NWJCC, from 2017–2018 to 2024–2025

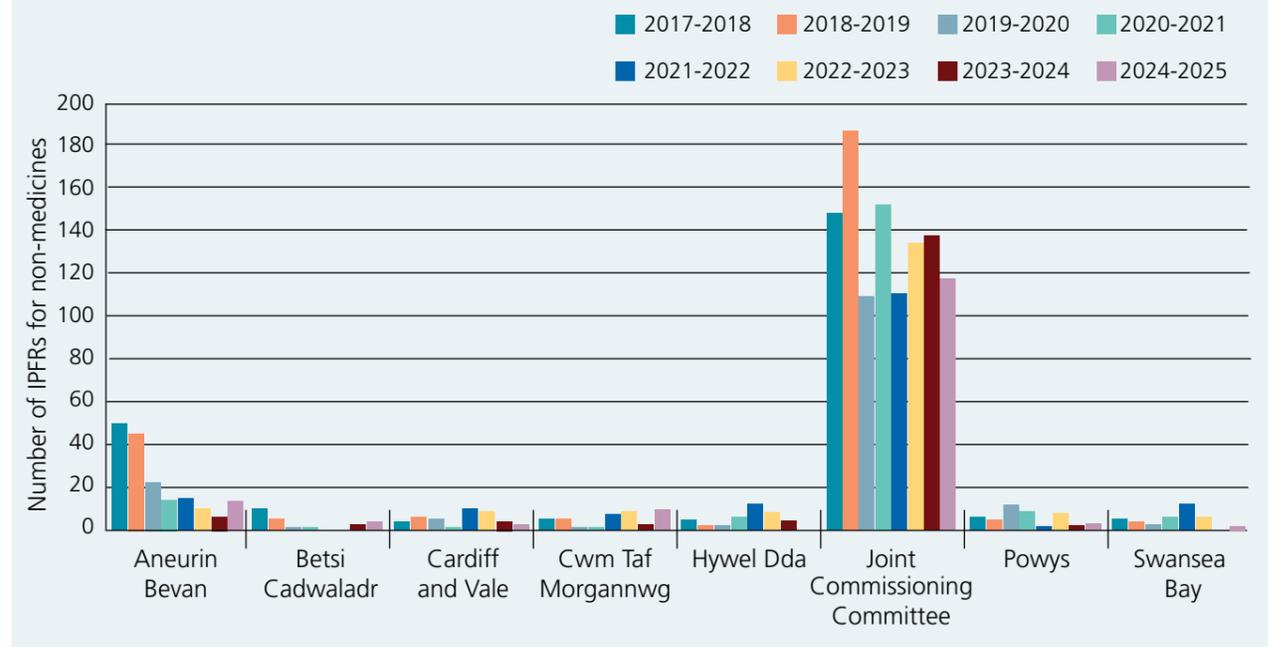


Figure 10: Number of IPFRs for non-medicines and per 100,000 population within each health board in Wales in 2024–2025

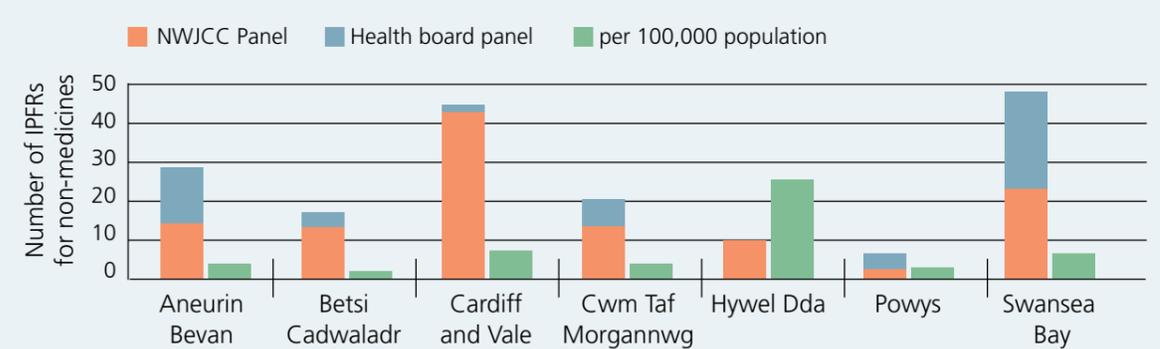


Figure 10 shows the number and rate of non-medicine IPFRs for each health board. The non-medicine IPFRs reported for NWJCC are added to the health board in which the patient resided. The highest number of non medicine IPFRs were for patients living in Cardiff and Vale UHB with 45 requests in 2024–2025, equating to 8.9 per 100,000 population. The lowest rate was reported for Betsi Cadwaladr UHB with rate of 2.3 per 100,000 population and a total of 16 requests. The lowest number of non medicine IPFRs was for Powys THB, where 5 requests

were reported in 2024–2025; this equated to 3.7 per 100,000 population. The rates ranged more widely in 2024–2025 than in 2023–2024, when the rate ranged between 3.7 and 5.9 non-medicine requests per 100,000 population.

The types of non-medicine interventions requested are shown in Figure 11. As in previous years the highest proportion (46%) of non-medicine requests in 2024–2025 was for positron emission tomography (PET) scans; this represents a rise from 42% in 2023–2024. The number of IPFRs for PET scans increased slightly from 67 in 2023–2024 to 69 in 2024–2025. Most (80%) of IPFRs for PET scans were for investigation of cancer conditions (Figure 12).

The conditions for which PET scans were requested in 2024–2025 were diverse, with only cancer of unknown origin requested multiple times. In 2024–2025 there were 4 requests for PET scans for cancers of unknown origin, in the previous year scans were requested 10 times for this condition. In 2023–2024 the PET scan policy was reviewed to consider including cancers of unknown origin; however, this was not approved due to the poor evidence base.

There were 34 requests for surgical procedures in 2024–2025, a decrease for the second year running from 56 requests in 2023–2024 and 73 in 2022–2023. Breast reduction surgery was the most requested surgical procedure with 5 requests; there were 4 requests each for abdominoplasty and for atrial appendage occlusion. All other surgical procedures were diverse with no more than 2 requests for any one procedure. Requests for cytoreductive surgery and hyperthermic intraperitoneal chemotherapy reduced again in 2024–2025 to fewer than 3; in 2023–2024 there were 6 requests and 10 in 2022–2023. Likewise, requests for stereotactic radiosurgery fell to fewer than 3 from 5 in the previous year and 7 in 2022–2023.

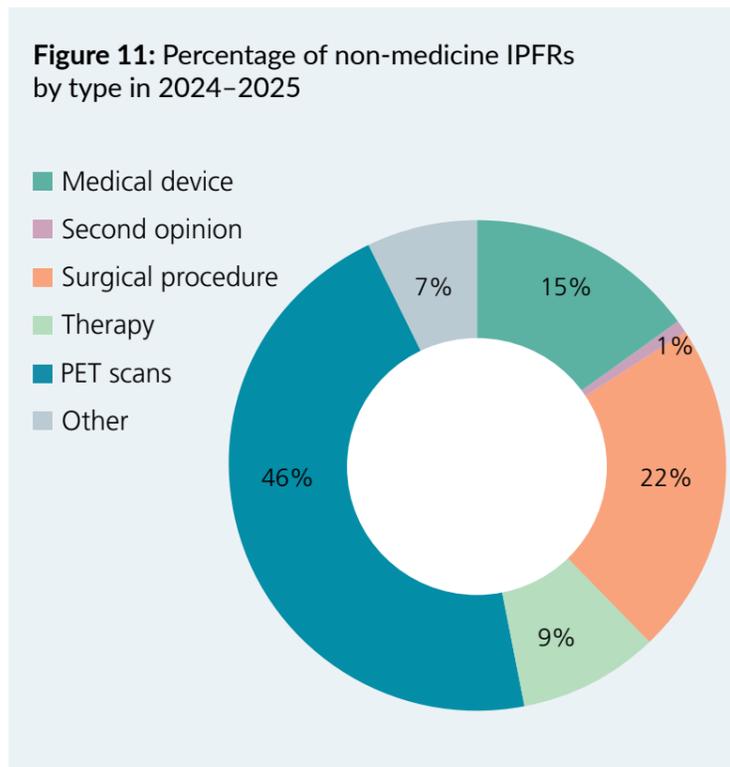
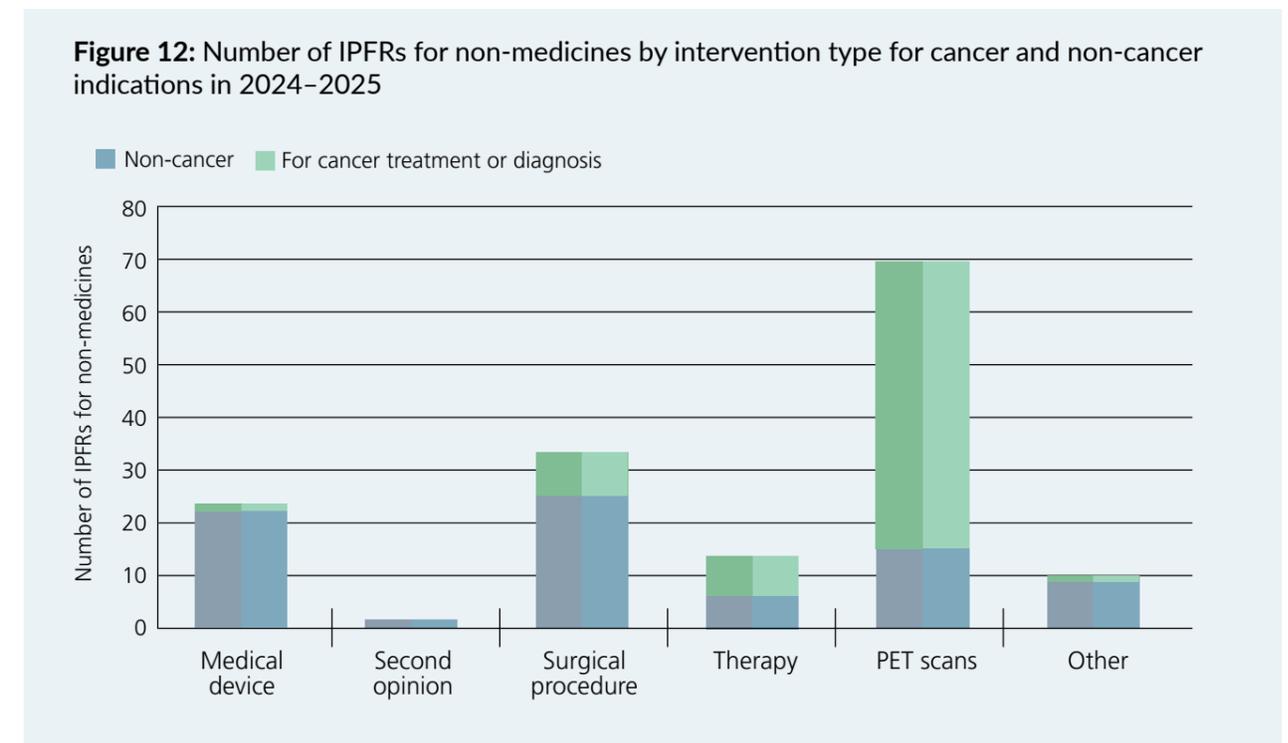


Figure 12 shows the proportion of non-medicine IPFRs for cancer and non cancer conditions. Overall, 51% of requests were for interventions for cancer conditions, most of those (71%, n = 55) for PET scans. There were 9 requests for surgical procedures for treatment of cancer conditions and 7 for therapies. Non-medicine IPFRs for non-cancer conditions accounted for most of the requested surgical procedures and for medical devices, with 25 and 22 requests in 2024–2025, respectively.



In 2024–2025 Health Technology Wales (HTW) continued to conduct rapid evidence summaries to provide additional information to support IPFR panel decision making. HTW received 18 requests for rapid evidence summaries, most were for therapies for treatment of functional neurological disorders (n = 7). Sixteen summaries were provided, 2 were not progressed as one was no longer required, and the other was not related to a specific intervention. AWTTC continue to provide HTW with a summary of potential non-medicine cohorts arising from collated IPFR data every 6 months to help identify potential areas of unmet need for consideration on a wider All Wales basis.

Panel activity

In 2024–2025 Cardiff and Vale UHB panel recruited one new member and extended the membership of the lay member for an additional 3 years. The IPFR team at Cardiff and Vale UHB also provided training to 2 public health consultants who are joining the IPFR rota. Training was also provided to the local vascular network manager for information on the IPFR service in Cardiff and Vale UHB.

Swansea Bay UHB IPFR team have updated their standard operating procedures (SOPs) and provided training to colleagues to ensure the wider team are up to date with local processes. The team have also completed an analysis of 5 years of IPFR, Prior Approval and Service Commissioning Gap requests, allowing for identification of any trends in the different funding routes. Swansea Bay UHB team are working on recruitment of lay members for the IPFR panel with an updated job description and advert. After a request for a review of a decision from the Swansea Bay UHB IPFR panel, the Chair and Vice Chair have worked with the team to develop an SOP for video recording of the panel meeting going forward. The Chair and Vice Chair, who were appointed in 2023–2024, have continued to work hard with the IPFR team in Swansea Bay UHB to make effective improvements to the panel and process locally to ensure a robust and thorough process.

In 2024–2025 Powys THB have initiated a review of differences in approach to the IPFR process between panels, including: cost thresholds, consideration of unlicensed medicines, and information provided to panel members. The team will be continuing with this work to advocate for standard approaches for all IPFR panels in Wales.

Patient outcomes

In 2024–2025 outcome data was available for 73 patients, all of whom had received treatment that was approved through IPFR. This represents outcome data for 18.5% of all IPFRs considered in the year, an increase on the 14.5% reported in 2023–2024.

In 41 (55%) cases outcome data had been provided as part of a request for continuation of funding treatment; the remainder were provided on completed IPFR outcome forms or by email on request by the IPFR teams.

The outcome data provide information on:

- the patient's response to treatment;
- effect on quality of life; and
- reasons for stopping treatment (if applicable).

All outcomes but one were reported for funded medicines. As in previous years, outcomes for non-medicine interventions were generally not reported. In some cases data were incomplete, so figures provided will not necessarily total 73 for all parameters.



In 15 cases treatment had been stopped; for the remaining 58 patients treatment was ongoing. Six of the patients who had stopped treatment had received the full course of treatment as planned. The remaining 9 patients had stopped treatment early: 4 after disease progression, 3 patients died whilst on treatment and 2 stopped due to treatment-related toxicity.

Seven patients did not start the treatment that had been approved; in 4 cases this was the patients' choice and in one case tests showed that the treatment would not be suitable for the patient. This may highlight an area for future clinician training to ensure that patients have consented to the IPFR application and that only treatments known to be suitable are requested. No reason was given for the remaining 2 patients who did not start treatment.

Reasons for stopping treatment

- 4 Disease progression
- 2 Treatment-related toxicity
- 3 Death

There were 5 deaths reported, either after or during treatment. During the course of treatment of these 5 patients the best responses reported were: complete response for one patient; partial response for 2 patients; stable disease for one patient; and the remaining patient had not been assessed for response. Three of the patients had an improved quality of life and 2 maintained their quality of life whilst on treatment.

As in previous years, in 2024–2025 the outcomes reported are associated with evidence of clinical benefit and improvement or maintenance of quality of life for patients receiving treatments approved by IPFR panels. It should be noted that a considerable number of the outcomes were associated with applications for continuation of funding. Therefore, most reports (55%) will relate to patients who are benefitting from an approved medicine.

AWTTC were pleased to report an increase in the number and proportion of IPFRs for which outcome data were available. In June 2024 an addition to the IPFR database landing page provides a list of applications for which the date set for collecting outcomes is due (for example, when treatment

Quality of life following or during treatment



would be expected to be completed). This is intended to prompt the IPFR teams to request completed outcome questionnaires at the most appropriate time in relation to treatment. The lack of outcome reporting for non-medicine interventions such as surgery, medical devices and one-off treatments is still lacking, as are outcomes for patients whose IPFR was declined.

AWTTC will work with panels and clinicians to explore ways to encourage outcome reporting for non-medicine interventions.

Quality Assurance Advisory Group

Quality assurance of the IPFR process showed that, overall, outcome measures were at a high level during 2024 although a slight decrease was observed compared with 2023. On average, 96% and 86% of IPFRs reviewed met the assessment criteria for the application and panel processes, respectively; 83% met the decision process criteria. This compared to averages of 97%, 87% and 83% for the application, panel and decision processes, respectively, during 2023.

The primary function of the IPFR Quality Assurance (IPFR QA) Group is to examine and address variation between IPFR panels in relation to consistency in the decision-making process. The Group is provided with all paperwork associated with a randomly selected IPFR from each quarter, including the application form, supporting documentation and correspondence with the applicant clinician. Paperwork is fully redacted by the local IPFR team to remove patient identifying details before it is sent to AWTTTC and shared with IPFR QA group members. Aspects of the application process, the panel process and decision process are assessed against pre-defined criteria and in line with the IPFR policy. The IPFR policy and Terms of Reference for the IPFRQA Group are available on the [AWTTTC website](#).

In the year 2024–2025, the Group met four times to assess IPFRs covering the 2024 calendar year. Figure 13 shows the percentage of criteria met annually from January 2018 to December 2024. The percentage of assessments meeting the criteria of all three processes fluctuated from between just under 80% to 100%, which corresponds to only a few criteria not being met each quarter. There was a marked decrease in the percentage of decision process criteria met during Quarter 2 in 2024 which was attributed to clinician and patient letters being sent outside the five-day timeline by three panels. The decrease in the percentage of panel process criteria met during in 2024 was partly attributed to some panels following a revised version of the IPFR Policy, despite an agreement for IPFR panels to follow the existing 2017 version during this calendar year.

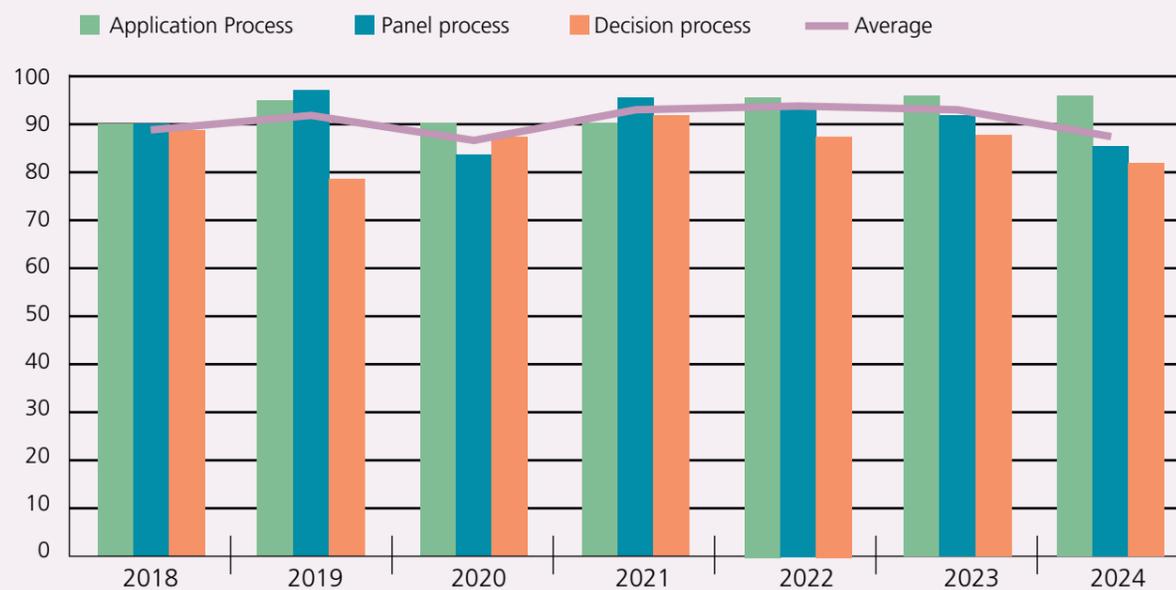
A detailed report is sent to each panel providing the IPFR QA group feedback on the application assessed, with an action plan to address any issues arising. Examples of good practice and any common themes are shared across all panels. A combined summary report of the IPFR QA group assessments is sent every six months to the Deputy Chief Medical Officer and to Pharmacy and Prescribing, Welsh Government.

Action points raised through these assessments have resulted in a general improvement in IPFRs over time, and continue to provide useful feedback on how the IPFR process can be further improved.

In 2024

- All but one of the 32 cases assessed met the urgency deadline.
- 5 of 7 panels met all criteria in at least 2 of the cases reviewed.
- In all cases assessed the IPFR process was being used appropriately

Figure 13: Annual percentage of IPFRs assessed that met the Quality Assurance process criteria between January 2018 and December 2024



Action points from 2023

- In 2022, the Group noticed a lack of public health representation for a couple of the panel meetings assessed although the panel was still deemed quorate. The QA Group were pleased to note that this issue had been resolved and attendance by public health representatives was back to pre-pandemic levels.
- The Group reminded panels that decision by Chair's action should be reserved for urgent cases only and applications should go to a full panel meeting whenever possible. After this reminder, the Group noted that Chair's action was used more appropriately during 2024.
- The economic evaluation of some cases and identifying appropriate comparators remained a source of difficulty for some panels. These issues were addressed at the IPFR workshop in May 2024 where sessions on comparators and economic evaluation were held. The Group still felt that economic considerations are sometimes limited although improvements are being noted most particularly around increased consideration of offset costs and associated treatment costs.
- Panels were reminded that a letter should always be sent to the patient except for patients who are in hospital. Panels were also reminded that letters to clinicians should be sent within 5 working-days of the decision and should include the decision rationale. Overall, improvements had been noted, and deadlines were missed only by a few days at most. In such cases, requesting clinicians have usually been informed of the decision by email in advance of the letter being sent.

- The Group had reminded panels to consider the specific clinical presentation of the patient's circumstances in every case. The Group were pleased to observe that panels did not refer to patient cohorts or past precedent in the cases assessed by the QA Group in 2024.

Action points from 2024

- The Group highlighted the terminology used by panels when considering value and the difference in meaning between 'cost effectiveness' and 'value for money', and that value for money is most likely to be considered for IPFR as a cost-effectiveness analysis is unlikely to be available. Although the Group were pleased to see some panels making a distinction between these concepts in their discussions, value for money considerations still appear to be limited for most panels, highlighting the need for more training on this topic.
- The QA Group highlighted the importance of fully capturing the rationale for decisions made by Chair's action where no discussion record is produced and most especially for applications not approved and that may be subject to subsequent review.
- Panels were reminded of the value of having pharmacy input for medicine applications and Health Technology Wales input for non-medicines. The Group encouraged panels to redact any confidential information and add evidence summaries to the evidence library on the IPFR database to support future similar IPFR applications.
- The Group observed inconsistencies between panel discussions, most particularly relating to those regarding Part 9B of the application form, despite agreement that IPFR panels would continue to follow the 2017 IPFR Policy until the revised policy had been formally signed off and adopted. Panels were reminded to follow the 2017 IPFR Policy until further notice to ensure consistency of decision-making across panels.

Members of the QA Group observed three panel meetings during 2024. For two of these meetings, the Group observer reported that cases were deferred by the panel because the submissions had insufficient information to make a decision. The Group will explore ways to offer more support to panels and clinicians to improve the quality of information provided in IPFR applications.

The Quality Assurance Advisory Group consider that overall, the IPFR process was generally being used for appropriate cases, was fair and was being followed in line with the IPFR policy.

Future action points

- The revised IPFR policy is due to be formally signed off and adopted by all panels in 2025–2026. The IPFRQA Group will ensure that any changes to process are applied to the criteria considered by the Group.
- A training section is being created on the AWTTTC website to store materials developed in collaboration between the Policy Implementation Group and the AWTTTC IPFR team. This will include resources for both clinicians and panels.
- Panels without lay representation will be encouraged to refer to the resources provided on the AWTTTC website and supported in the recruitment of new lay members.

Policy Implementation Group

The NHS Wales IPFR Policy Implementation Group (PIG) provides a strategic and collaborative forum that supports the consistent, transparent, and fair application of the IPFR Policy across all health boards and NWJCC.

The Group includes representatives from each health board, NWJCC, AWTTTC and HTW. It plays a key role in guiding decisions around treatments and interventions that fall outside the range of services routinely provided or commissioned by health boards or NWJCC. This includes requests for routine treatment outside a patient's local area (Prior Approval Process), Interventions Not Normally Undertaken (INNU), and treatment within the European Economic Area under the S2 process.

Through its work, the PIG helps shape policy and supporting materials, encourages the sharing of good practice, and promotes ongoing improvement. It ensures that IPFR-related policies remain up-to-date, clear, and aligned with national standards, while fostering a consistent approach across Wales.

The group also works to improve understanding of the IPFR process among clinicians and patients, supports high-quality data collection to meet reporting needs, and monitors emerging risks to help inform preventative and responsive strategies.

In partnership with AWTTTC, the PIG contributes to the development of the annual IPFR report and uses insights from the process to inform future regional and national commissioning opportunities.

In 2024-2025 the group have provided valuable input for IPFR database developments, in particular to help AWTTTC to identify users of the electronic submission (e-submission) facility. This has enabled AWTTTC to consult with users and identify improvements for the e-submission process to encourage wider uptake. They have also contributed to the training of panel members and clinicians through local initiatives and have shared locally developed training materials with the group. The group have continued to promote the use of HTW evidence reviews to support non-medicine IPFR decision making.

Meaningful engagement with key stakeholders is central to the Group's approach, helping ensure the IPFR process remains inclusive, responsive, and fit for purpose. The Group also promotes strong collaboration across Wales, with a shared commitment to supporting one another and delivering consistent, patient-centred care.

Summary of the data

Overall, the data for 2024–2025 show:

403

IPFRs were processed across Wales



an increase of 9 compared with 2023–2024

19

(7%) more requests for medicines in 2024–2025 compared with the previous year



83%

of all IPFRs were approved



4% increase compared with the previous year

42%

requests for cancer treatments



fell from 52% to 42% this year

79%

of people for whom data was available had a complete or partial response to their IPFR-funded treatment



78%

had an improvement in their quality of life

Glossary and additional note

AWMSG	All Wales Medicines Strategy Group
AWTTC	All Wales Therapeutics and Toxicology Centre
HTA	Health Technology Assessment
HTW	Health Technology Wales
IPFR	Individual Patient Funding Request
Licence	Marketing authorisation
Medicine	A drug or other preparation for the treatment or prevention of disease
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
Off-label	Medicine used outside the terms of the marketing authorisation (product licence)
OWMAG	One Wales Medicines Assessment Group
PET	Positron emission tomography
NWJCC	NHS Wales Joint Commissioning Committee

Additional note

Where small numbers are involved, we are unable to provide the names of specific treatments because the potential risk of identifying individual patients becomes significant. Therefore, this information is considered personal information and is withheld under Section 40(2) of the Freedom of Information Act 2000. The information is protected by the Data Protection Act 1998, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles set out in Schedules 2 and 3 of the Act.