



AWTTC

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



Individual Patient Funding Request (IPFR)

Annual Report 2023-2024



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

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AWTTC Clinical Director's statement

Whilst Team GB is going for gold this summer in Paris we look back at the wins for the IPFR process in Wales for 2023–2024.



Prof James Coulson
Clinical Director, AWTTC

The number of IPFRs being considered in Wales is continuing to rise; in 2023–2024 IPFR requests rose by 17% to 392 when compared to the previous year, driven by a 45% increase in medicine requests, half of these due to a handful of medicines. Requests for non-medicines fell slightly by 12% to 159. Requests rose for four of the eight panels in Wales with the Joint Commissioning Committee receiving the most requests. Approval rates remain high at 79%, the same as the previous year.

The IPFR workshop received fantastic feedback, with the gold medal for the most positive feedback going to the training session with clinicians on how to complete IPFRs. It was satisfying to see so many clinicians attending on the day to learn more about the process and how they can improve their applications. A very moving video showed an interview with a patient on their experience of IPFR, and really set the scene for how important these decisions are for patients and how life changing the impact of those decisions can be.

Changes to the IPFR policy are ongoing. We hope these changes will provide much needed clarity around the decision-making process so that we can ensure consistency in our approach across Wales. I am also encouraged that no independent reviews were carried out this year.

As Chair of the IPFR Quality Assurance process I am heartened to see continued improvements in the application process at a local level. For this category we are checking to see that the IPFR process is being used for appropriate requests and it also focusses on the timeliness of decisions and ensuring that the appropriate information is available to panels on which to make a decision. Overall documentation of decisions remains good, with panels adhering to the use of a proforma that provides clarity of their discussions and decision rationale. This all makes for a smoother process for clinicians and patients, but with an appropriate level of rigour to ensure that scarce NHS resources are being used appropriately. There have been some issues in relation to the timeliness of letters reaching clinicians and patients, but this represents only a few cases and clinicians are contacted by email to speed up decisions.

Panels across Wales continued to develop and improve their internal IPFR processes. Cwm Taf Morgannwg University Health Board (UHB) and Swansea Bay UHB have appointed new IPFR panel chairs and have been working to strengthen and streamline processes. Cardiff and Vale UHB have provided training to a cohort of public health speciality registrars.

Powys Teaching Health Board (THB) panel continue to develop their internal processes and are looking at ways to improve their value-for-money considerations, seeking health economic support from AWTTC for some of their reports.

It is excellent to see local panel initiatives to develop and improve IPFR service provision and we wish all the panels in Wales continued success in the coming year.

Executive summary

- In 2023–2024 the total number of IPFRs across Wales increased to 392 from 335 in 2022–2023. There were large increases in requests for medicines, up by 45% and a drop in requests for non-medicines by 12%.
- Powys Teaching Health Board continued to have the highest rate of IPFRs per 100,000 population.
- The Joint Commissioning Committee had the highest number of medicine and non medicine IPFR requests. Two health boards also saw a substantial increase in medicine-related requests.
- The number of IPFRs approved remained static with 79% of all IPFRs approved in 2022–2023 and 2023–2024.
- The approval rate for medicine IPFRs decreased from 85% in 2022–2023 to 81% in 2023–2024.
- The approval rate for non-medicines continues to rise; up to 77% in 2023–2024 from 73% in 2022–2023 and 70% in 2021–2022.
- The percentages of patient outcomes reported in 2023–2024 was 14.5% of all IPFRs considered. Overall, 67% of people were reported to have a complete or partial response to treatment, down on last year (77%), and 67% had an improvement in quality of life, again lower than last year (70%).
- Between 88% and 97% 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.
- AWTTTC hosted the seventh annual IPFR workshop at Cardiff City Stadium in May 2024; the workshop was well received. Videos and presentations from the workshop can be viewed on the AWTTTC website.
- As of March 2024, there were 19 published One Wales decisions on medicines; 18 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 Joint Commissioning Committee, working on behalf of the seven health boards in Wales, commissions specialised services at a national level. However, each year, the health boards and the Joint Commissioning Committee receive requests for healthcare that fall outside the range of services agreed.

An Individual Patient Funded Request (IPFR) is defined as ‘a request to a health board or the Joint Commissioning Committee to fund NHS healthcare for an individual patient 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 by:

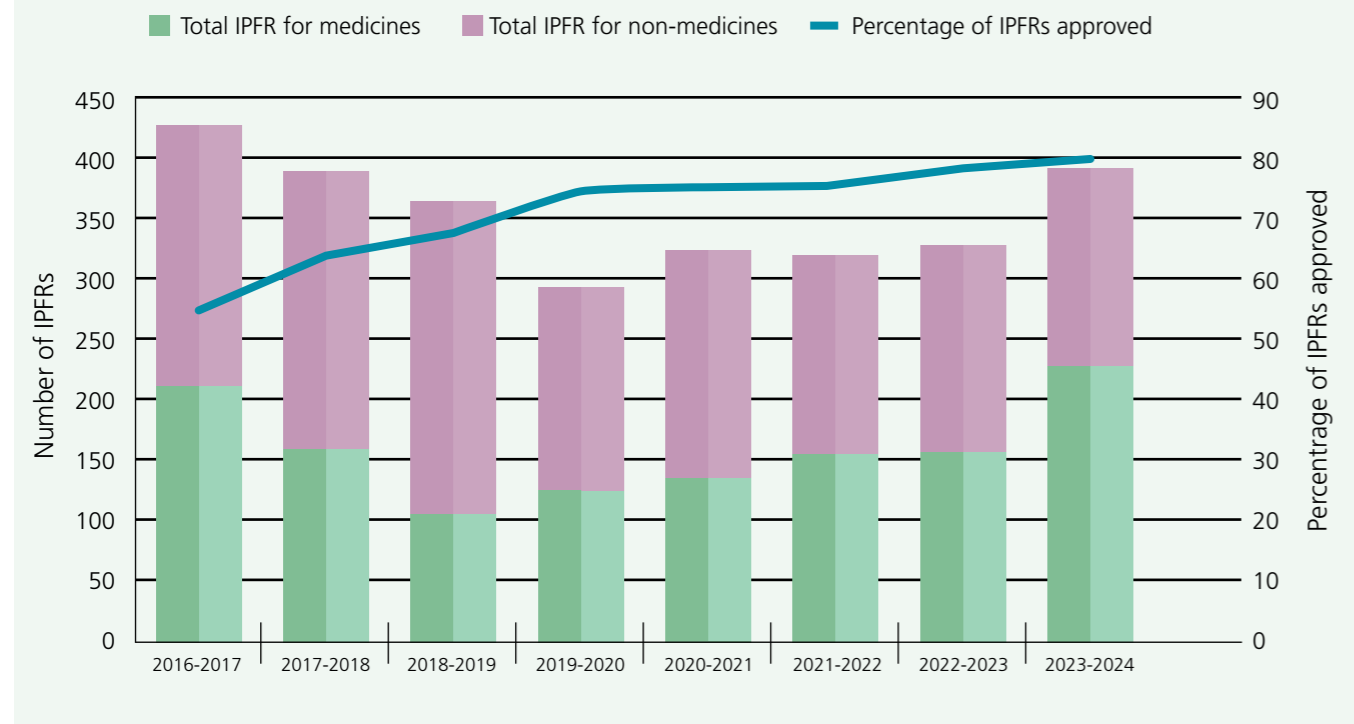
- developing and updating the IPFR database;
- audit and maintenance of the quality and desired level of service;
- identifying cohorts and medicines for the One Wales Medicines Process; and
- hosting an annual workshop and training event for members.

Individual Patient Funding Requests

Between 1 April 2023 and 31 March 2024, panels in Wales considered a total of 392 IPFRs. This is a marked increase compared with 2022–23 when a total of 335 IPFRs were considered, and is the highest number recorded since 2016–2017 (Figure 1).

Of the 392 IPFRs, 234 were for medicines and 159 were for non-medicines; 1 request was for both a medicine and a non-medicine. In 2023–2024 the number of requests for medicines increased, whilst requests for non-medicines decreased compared with 2022–2023. Overall, 52% of all IPFRs in 2023–2024 were for interventions for cancer conditions.

Figure 1: Total number of IPFRs considered in Wales from 2016-2017 to 2023-2024



The approval rate for all IPFRs in 2023–2024 was 79%, the same as in 2022–2023.

The increase in IPFRs considered in 2023–2024 was driven by increases in IPFRs for 4 of the 8 panels (see Figure 2). The largest increase was reported for the Joint Commissioning Committee, who considered 189 IPFRs in 2023–2024 compared with 154 the previous year representing an increase by 35 IPFRs.

Betsi Cadwaladr University Health Board (UHB), Cardiff and Vale UHB and Cwm Taf Morgannwg UHB also reported increases in IPFRs in 2023–2024 of 16, 14 and 4 IPFRs, respectively. Hywel

Dda UHB considered the same number as in the previous year, whilst Aneurin Bevan UHB, Powys Teaching Health Board (THB) and Swansea Bay UHB recorded falls in IPFRs of 3, 2 and 7, respectively.

Figure 2: Number of IPFRs within each health board in Wales, including the Joint Commissioning Committee, from 2016–2017 to 2023–2024

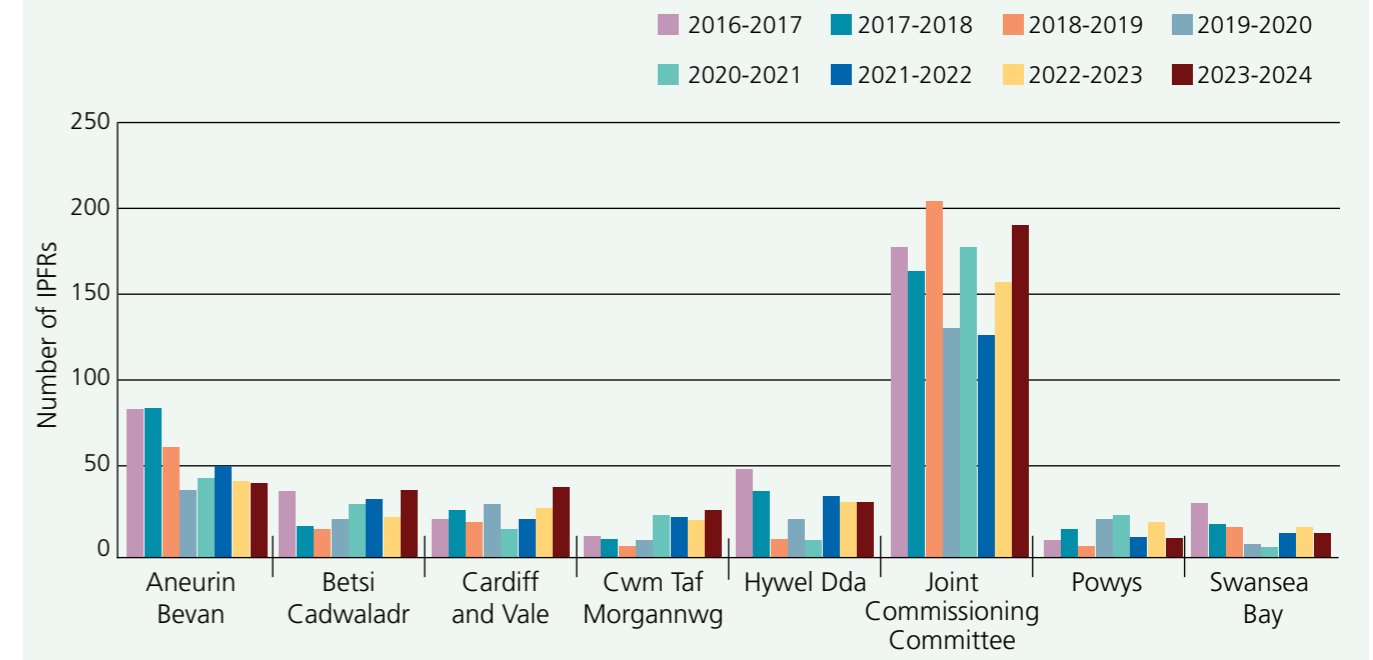
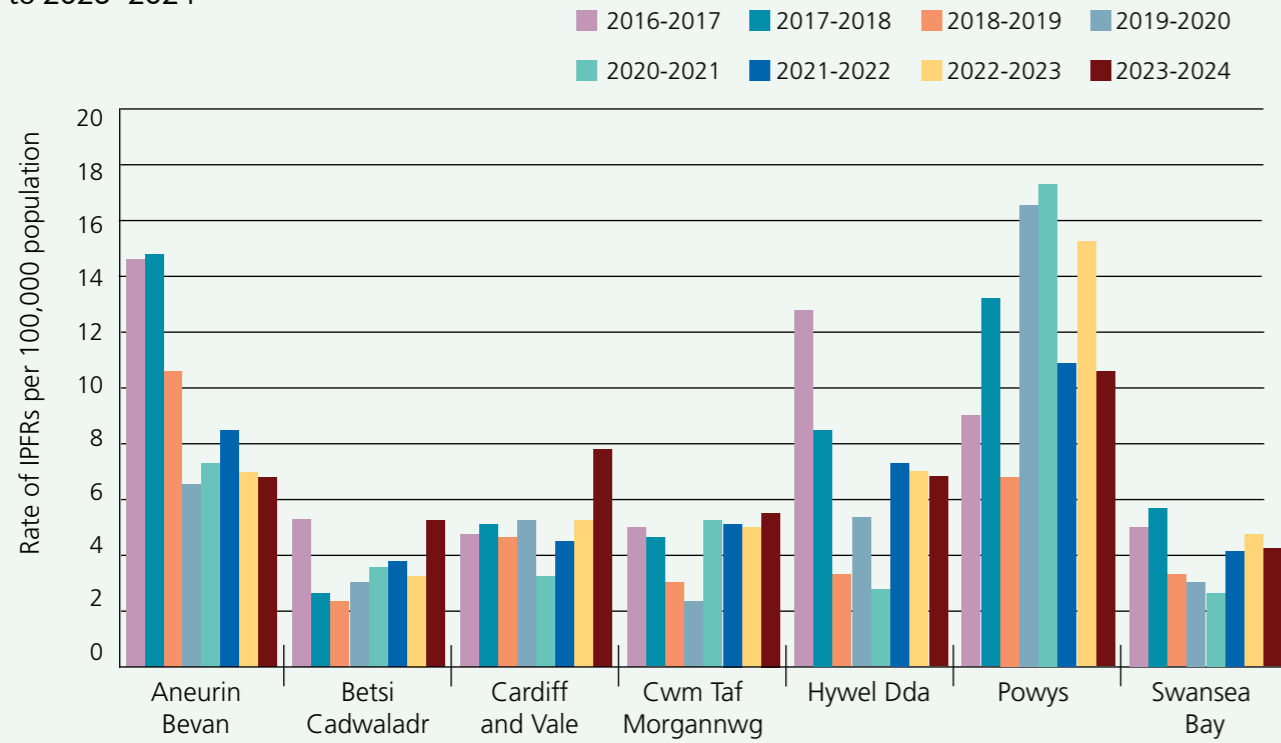


Figure 3 shows the rate of IPFRs considered by health board panels per 100,000 population. Despite a drop from 15.7 to 10.5, Powys THB continue to consider the highest number of IPFRs per 100,000 population. This is to be expected as Powys THB commissions services from English and Welsh providers. In all health boards the rate of IPFRs per 100,000 population decreased or increased in line with the respective numbers of IPFRs.

Figure 3: Rate of IPFRs per 100,000 population for each health board in Wales from 2016–2017 to 2023–2024



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. The number of requests did not differ greatly from the previous year, with 41 requests for continuation of funding; 37 requests were for medicines and 4 were for a combination of medicine and non-medicines. Powys THB considered the majority of continued funding requests (60%), most likely due to the high level of commissioned services from providers in England and Wales. All continued funding requests in 2023–24 were approved.

Independent reviews

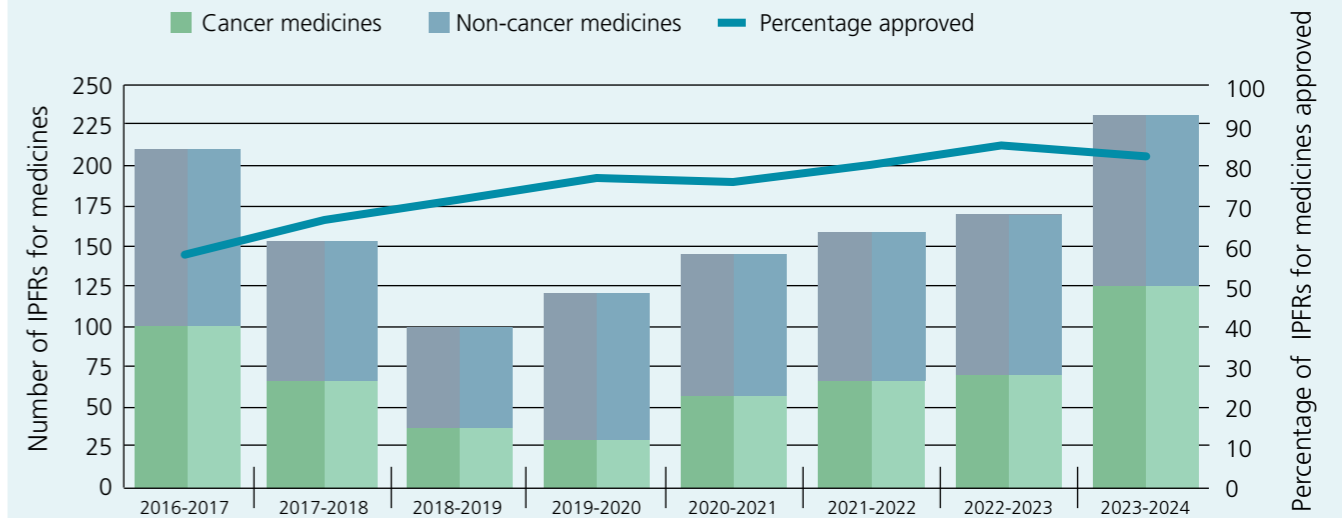
For IPFRs that are reviewed but not recommended by the panel, and where the patient and their clinician feel that the IPFR process has not been followed according to the IPFR policy, they may ask for an independent review of the IPFR process. We are pleased to report that no reviews were undertaken in 2023–2024.

IPFRs for medicines by health board and Joint Commissioning Committee

During 2023–2024 the number of IPFRs for medicines increased to 234, compared with 161 during 2022–2023 (Figure 4). IPFRs for medicines have increased each year since 2018–2019.

A total of 191 IPFRs for medicines were approved; 35 were not approved and 8 IPFRs were deferred. The approval rate of IPFRs for medicines was 81%, a decrease from 85% in 2022–2023.

Figure 4: Number of IPFRs for medicines considered in Wales from 2016–2017 to 2023–2024 and the percentage approved



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

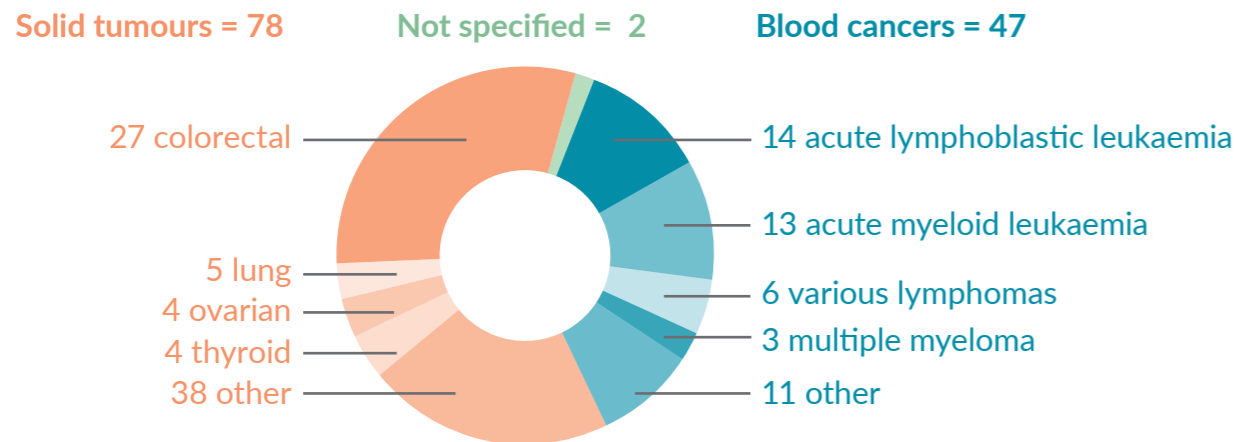
- Advice in relation to a licensed indication for that medicine is not available from the All Wales Medicines Strategy Group (AWMSG) or the National Institute for Health and Care Excellence (NICE).
- AWMSG or NICE has given advice, and has not recommended the medicine or is unable to recommend it.
- 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.

The mean annual number of IPFRs for medicines per health board reduced significantly year on year from 41 in 2015–2016 (not included in Figure 4) to a low of 11 in 2018–2019. Since 2018–2019 the mean annual number of IPFRs for medicines has increased annually to 26 in 2023–2024.

The fall in requests from their peak in 2015–2016 is thought to be due to a better awareness of the most appropriate routes for accessing medicines in Wales. Also, IPFRs were no longer submitted for certain indications after a positive One Wales Medicines decision was published. A small rise from 2019–2020 is likely to be linked to the COVID-19 pandemic; in particular to avoid hospital attendance for routine drug administration, especially for immunosuppressed patients through the use of non-routinely commissioned oral treatments or less immunosuppressant alternatives. As medicine requests continue to increase year-on-year it is likely that other factors are now affecting rates.

During 2023–2024, the number of IPFRs for medicines to treat cancer was 127, a 74% increase from 73 during 2022–2023 (Figure 4). IPFRs for other medicines (non cancer) increased to 107, compared with 88 during 2022–2023, a 22% increase. Overall, 54% of medicine requests were for cancer interventions, compared with 45% in 2022–2023. Most cancer interventions were for treatment of solid tumours; colorectal cancer was the most frequent, accounting for 39 medicine IPFRs.

Medicine requests for cancer indications = 127



Medicine requests for non-cancer indications were diverse with 14 requests for irritable bowel syndromes including Crohn's disease, ulcerative colitis and microscopic colitis. There were 9 requests for eosinophilic conditions, 5 of which were for treatment of eosinophilic granulomatosis. The medicines requested to treat these conditions differed and so no specific cohorts for non-cancer medicines and indications were identified. The remaining 88 non-medicine requests did not number more than 3 for any one indication.

The most common classes of medicines requested were monoclonal antibodies and tyrosine kinase inhibitors. This is not surprising as numerous medicines fall into these two classes and these modes of action can be used to treat a range of cancer and non-cancer conditions.

Most common classes of medicines requested:

Monoclonal antibodies;



Tyrosine kinase inhibitors;



The most commonly requested medicine was bevacizumab in combination with trifluridine plus tipiracil (Lonsurf®) for the treatment of metastatic colorectal cancer, with 14 requests. These requests follow publication of results from the Sunlight clinical study in which the combination of bevacizumab and trifluridine plus tipiracil showed longer overall survival for metastatic colorectal cancer patients compared with trifluridine plus tipiracil alone. Bevacizumab in combination with trifluridine plus tipiracil is being appraised by the National Institute for Health and Care Excellence (NICE); should NICE recommend this treatment, once the advice is published it would be expected that IPFRs for this combination would no longer be submitted.

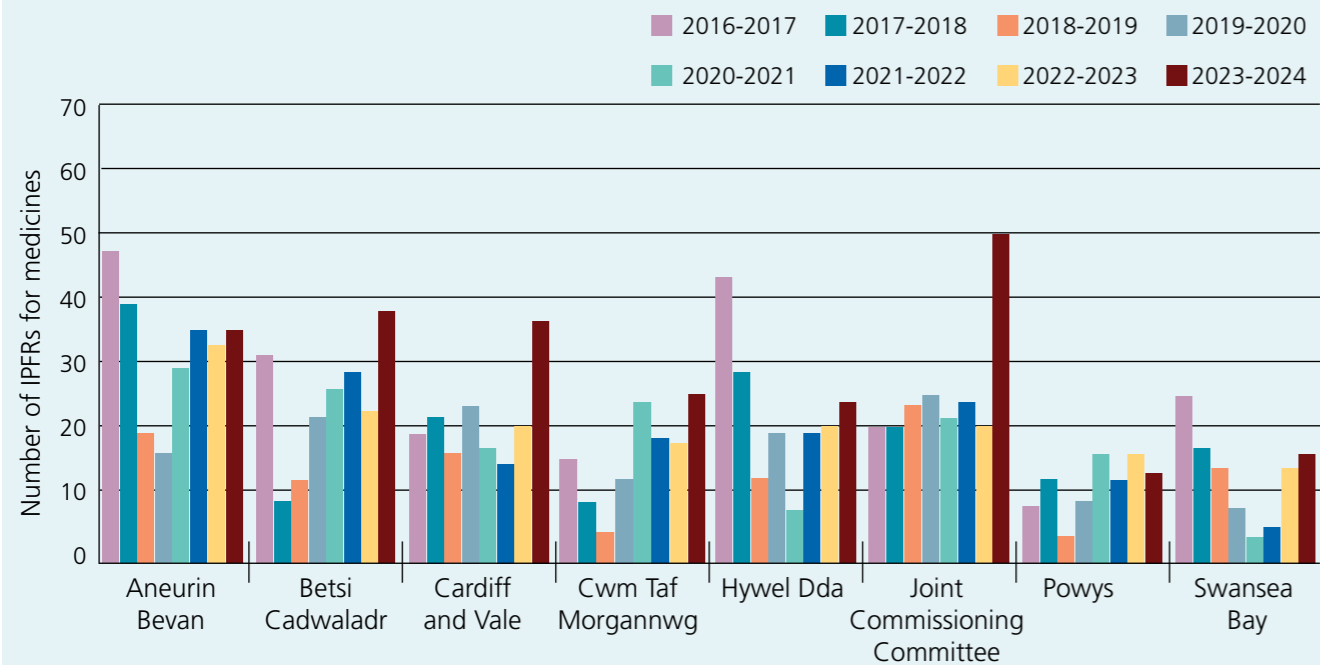
There were 11 requests for azacitidine in combination with venetoclax for treatment of relapsed acute myeloid leukaemia. This is an off-label use and AWTTTC have approached clinicians to consider submitting a request for access through the One Wales Medicines process.

The third and fourth most commonly requested medicines were both considered by the Joint Commissioning Committee panel. Six requests for blinotumomab for treatment of acute lymphoblastic leukaemia in children, and five requests for ruxolitinib for treatment of graft versus host disease. A commissioning policy for ruxolitinib is currently in progress with the Joint Commissioning Committee.

There were 12 requests considered by panels for pembrolizumab for 9 different types of cancer, and 8 requests for nivolumab for 5 different types of cancer. All other IPFRs for the same medicine and indication numbered less than 3 requests.

Figure 5 shows the numbers of IPFRs for medicines by health board and Joint Commissioning Committee over the past eight years. Of the 234 IPFRs during 2023–2024, Joint Commissioning Committee had the highest number (50 requests), followed by Betsi Cadwaladr UHB with 38; Cardiff & Vale UHB with 36 and, Aneurin Bevan UHB with 34.

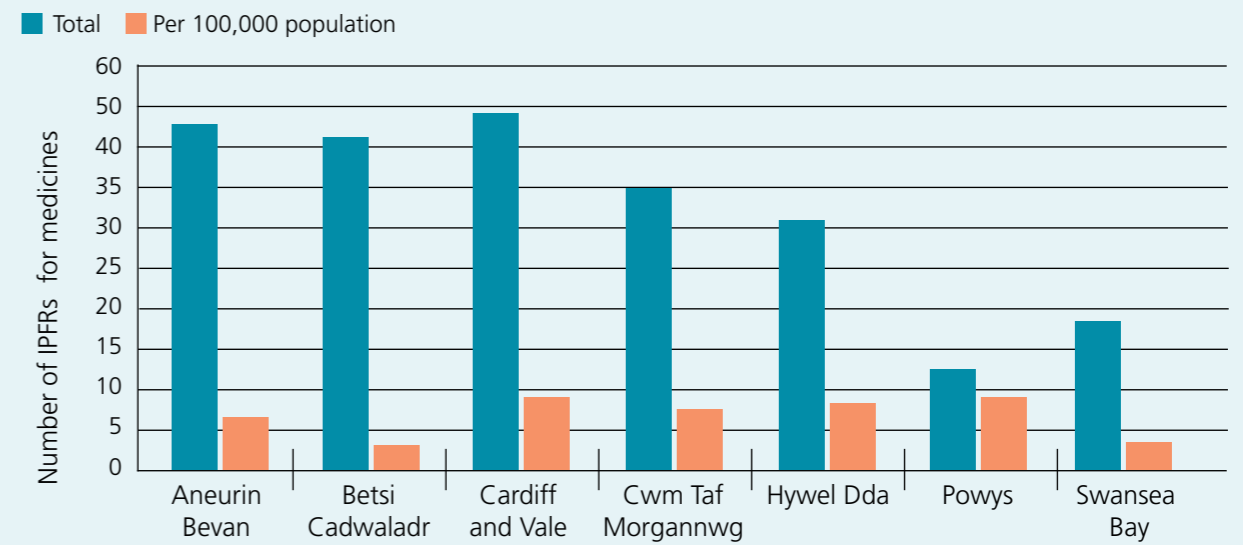
Figure 5: Number of IPFRs for medicines within each health board in Wales, including Joint Commissioning Committee, from 2016–2017 to 2023–2024



During 2023–2024, Powys THB was the only health board that showed a decrease in IPFRs for medicines compared with 2022–2023. Of the remaining six health boards, two showed bigger increases in IPFRs: Cardiff and Vale UHB increased to 36 (from 20 in 2022–2023), and Betsi Cadwaladr UHB increased to 38 (from 23 in 2022–2023). The largest increase in IPFRs was seen for Joint Commissioning Committee with 50 requests in 2023–2024 (from 20 in 2022–2023).

AWTTC will continue to monitor cohorts of medicine IPFRs for the same indication and, where appropriate, investigate routes for routine access in Wales.

Figure 6: Number of IPFRs for medicines and per 100,000 population within each health board* in Wales in 2023–2024



*Including the Joint Commissioning Committee non-medicine IPFRs for each health board

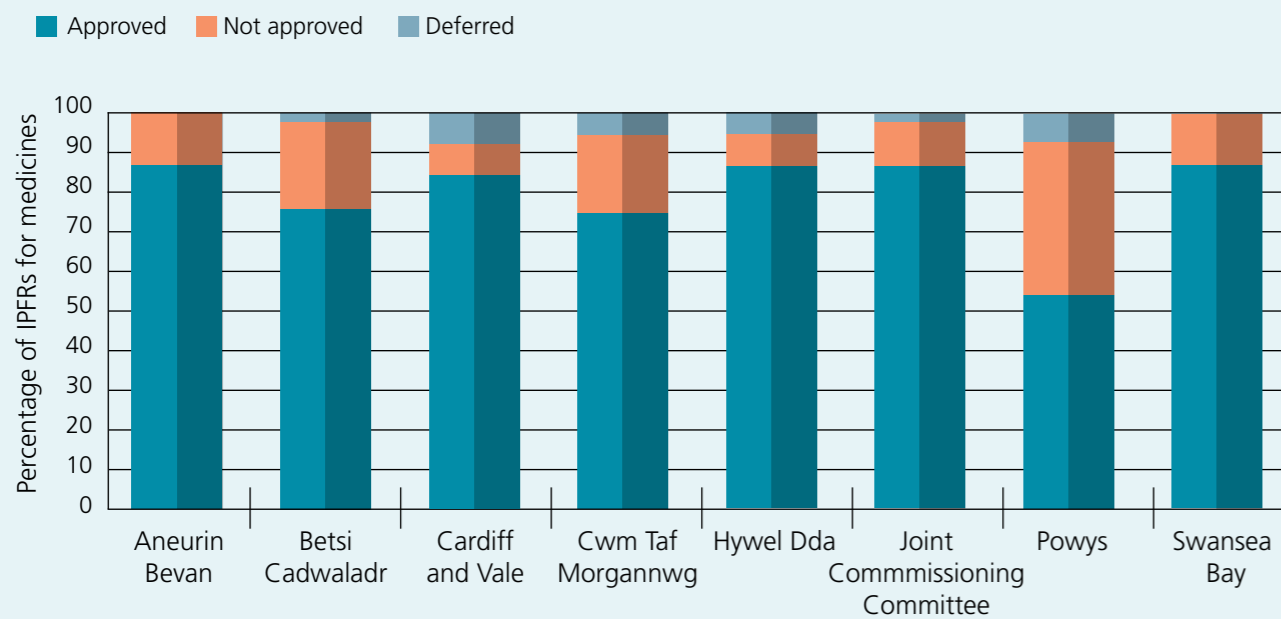
Figure 6 shows the rates of IPFRs for medicines per 100,000 population for each health board in Wales during 2023–2024. IPFRs for medicines received by Joint Commissioning Committee have been added to the local panel medicine IPFRs for each health board. The numbers of IPFRs for medicines per head of population ranged from 5 per 100,000 in Swansea Bay UHB to 10 per 100,000 in Cardiff and Vale UHB and Powys THB.

Differences between the rates of medicine IPFRs considered by panels may be due to differences in screening processes. Some panels have cost thresholds below which medicines are not considered through the IPFR process. Health boards may have other routes for considering off-label or unlicensed medicines. Powys THB, who consider a high rate of medicine IPFRs per 100,000 population have no cost threshold and consider all off-label or unlicensed medicines through IPFR.

The IPFR Policy Implementation group and AWTTC will continue to work with health boards to promote consistency of approach across NHS Wales.

During 2023–2024 the percentage of IPFRs for medicines approved by each health board and Joint Commissioning Committee ranged from 54% to 88% (Figure 7). Five health boards and Joint Commissioning Committee approved 80% or more of IPFRs for medicines. Powys THB had the lowest approval rate. Differences in the quality and appropriateness of requests affects the approval rate. It is difficult to compare them directly because the overall numbers of IPFRs for medicines were small for some health boards, in particular Powys THB and Swansea Bay UHB. In these health boards a small change in the number approved can markedly affect the percentage approval rate.

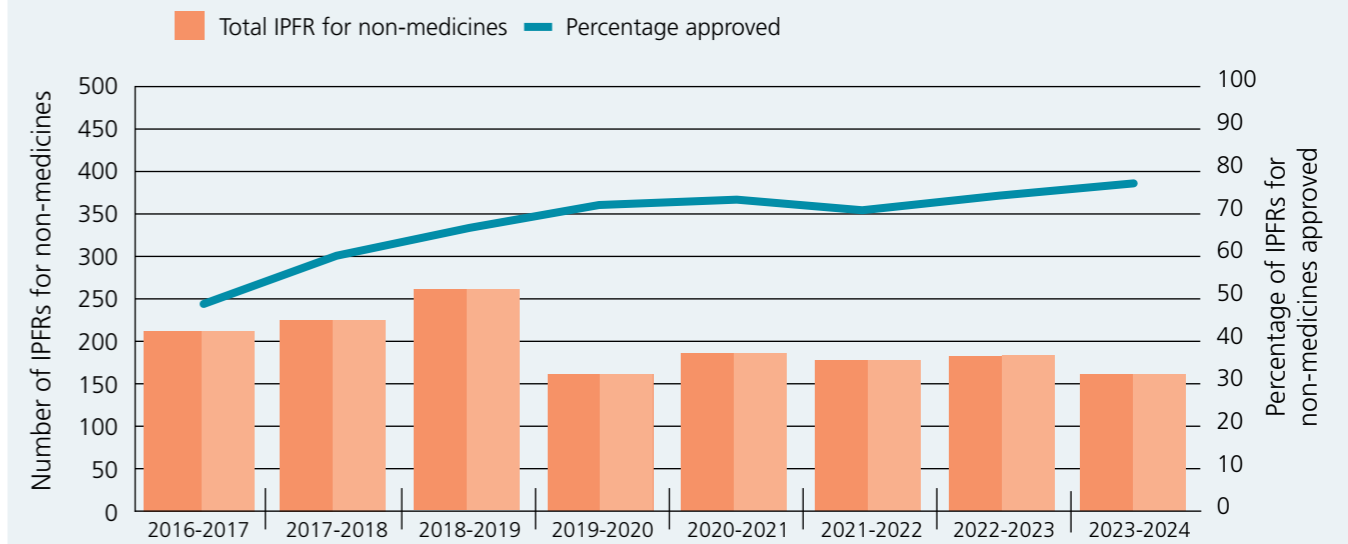
Figure 7: Percentage of IPFRs for medicines approved and not approved within each health board in Wales and Joint Commissioning Committee in 2023–2024



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

During 2023–2024 the number of IPFRs for non-medicines fell to 159 compared with 181 in 2022–2023. The approval rate for non-medicine IPFRs increased in 2023–2024 to 77% from 73% in the previous year. During 2023–2024 the number of non-medicine IPFRs approved was 123 and 36 were not approved (Figure 8).

Figure 8: Number of IPFRs for non-medicines and percentage approved between 2016–2017 and 2023–2024



In 2023–2024 the number of non-medicine IPFRs was 159, a decrease from 181 in the previous year and the lowest number recorded since 2015–2016 (not included in Figure 8) when these data were first collected (Figure 8). The data also show an overall upward trend in the approval rate for non-medicines, with 77% in 2023–2024, the highest rate reported since 2015–2016 (60% approved). Panels have reported an improvement in the quality of applications and supporting information provided, which may contribute to the increase in the percentage of IPFRs approved.

As in previous years, during 2023–2024 the Joint Commissioning Committee considered the majority (87%) of non-medicine IPFRs (n = 139), with the number little changed from the previous year (Figure 9). The decrease in non-medicine IPFRs overall results from a fall in the number considered by the health board panels combined, with all but one reporting a decrease of between 5 and 3. Betsi Cadwaladr UHB reported an increase from 0 to 1 in 2023–24. However, overall the number of non-medicine IPFRs considered by health board panels is low (n = 20) and so these changes are unlikely to be significant.

Figure 9: Number of IPFRs for non-medicines within each health board in Wales, including the Joint Commissioning Committee, from 2016–2017 to 2023–2024

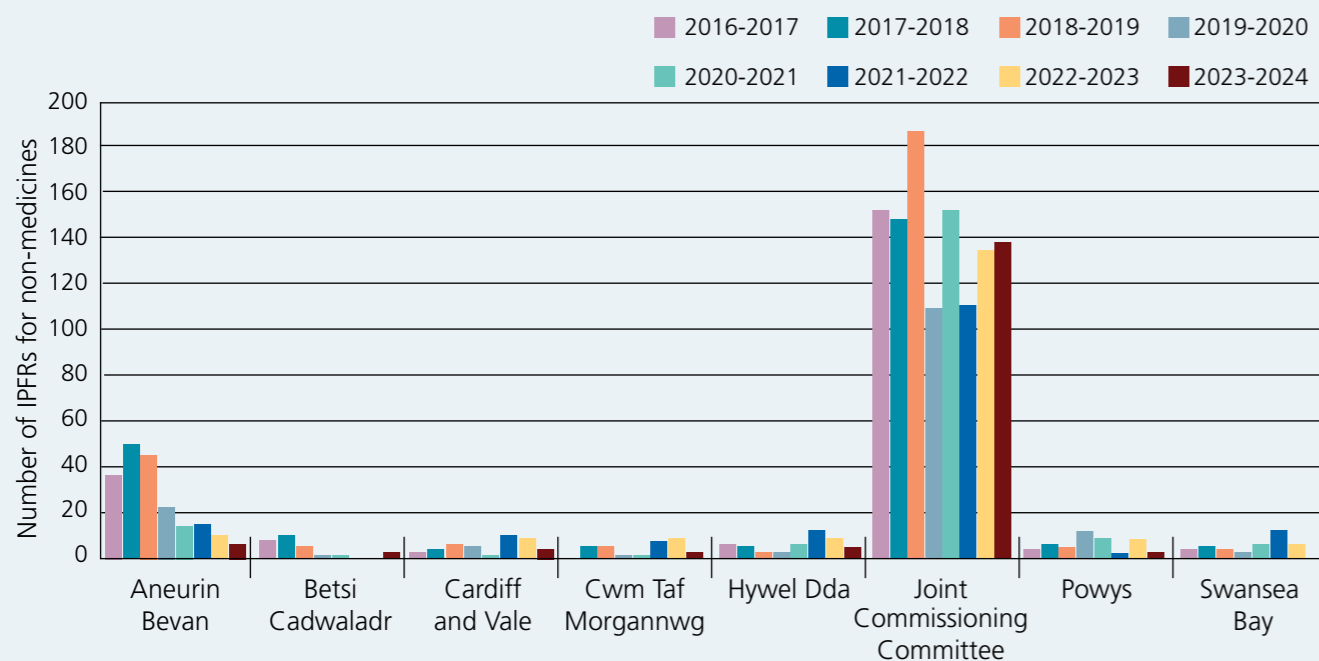
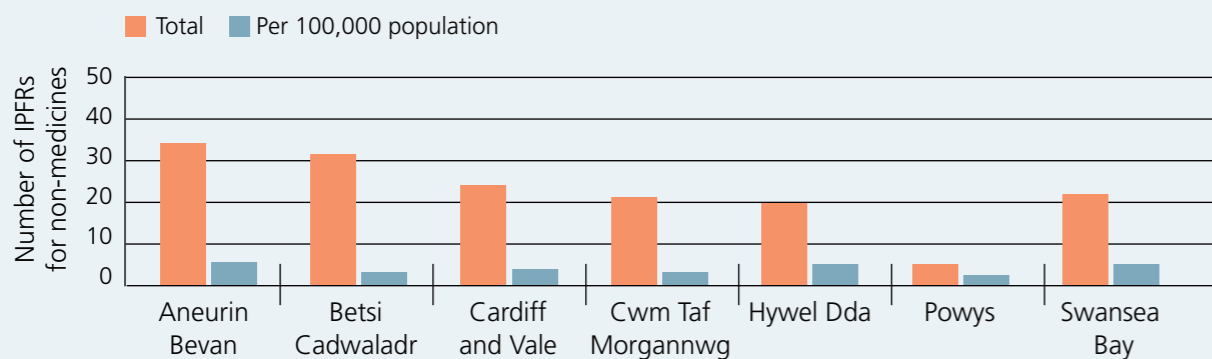


Figure 10: Number of IPFRs for non-medicines and per 100,000 population within each health board* in Wales in 2023–2024



*Including the Joint Commissioning Committee non-medicine IPFRs for each health board

Figure 10 shows the numbers of non-medicine IPFRs and rate per 100,000 population for each health board in Wales. All Joint Commissioning Committee non-medicine IPFRs have been added to the health board from which they originated. The rate of non-medicine IPFRs per 100,000 population is similar across most health boards, and ranges from 3.7 in Powys THB to 5.9 in Aneurin Bevan UHB. The range is narrower than the previous year when between 2 and 9.5 non medicine IPFRs per 100,000 population were considered for health boards.

The types of non-medicine requested through IPFR in 2023–2024 are shown in Figure 11. Positron emission tomography (PET) scans accounted for the largest proportion of non-medicine requests in 2023–2024. Requests for PET scans has increased for a second year running, up from 48 (23%) in 2022–2023 to 67 (42%) in 2023–2024. Most PET scans (n = 49) were for cancer conditions; with 10 for investigation of cancers of unknown origin (Figure 12). There were 8 PET scan IPFRs each for lung and prostate cancer, and 6 for colorectal cancer. Of the 18 PET scan IPFRs for non-cancer-related conditions, there were 5 requests where the diagnosis was not known; the remaining 13 were for a variety of conditions.

The All Wales PET Group work with the Joint Commissioning Committee to review the PET scan policy annually. In 2023–2024 cancers of unknown origin were considered for inclusion but were not approved because of the poor evidence base.

There were 56 requests for surgical procedures in 2023–2024, a decrease from the previous year when surgical procedures accounted for the largest proportion of non-medicine requests (n = 73; 35%). In 2022–2023 the comparatively high number of requests for surgical interventions was largely driven by requests for in vitro fertilisation (IVF); in part due to a backlog in referrals after the COVID-19 pandemic. There were 23 requests for IVF in 2022–2023, this has fallen to fewer than five in 2023–2024.

In 2023–2024 the number of IPFRs for microprocessor-controlled knee (MPK) devices continued to increase with 10 requests; there were 5 IPFRs in 2022–2023 and none in 2021–2022. The MPK commissioning policy was published by the Joint Commissioning Committee in 2021; the increase in IPFRs is likely to be for patients who do not meet the policy’s inclusion criteria. There was an increase in the number of IPFRs for cryopreservation of eggs or sperm, from 4 in 2022–2023 to 8 in 2023–2024. The number of requests for cytoreductive surgery and hyperthermic intraperitoneal chemotherapy and for stereotactic radiosurgery fell in 2023–2024, from 6 and 5 IPFRs, respectively, compared with 10 and 7 in 2022–2023.

Figure 11: Percentage of non-medicine IPFRs by type in 2023–2024

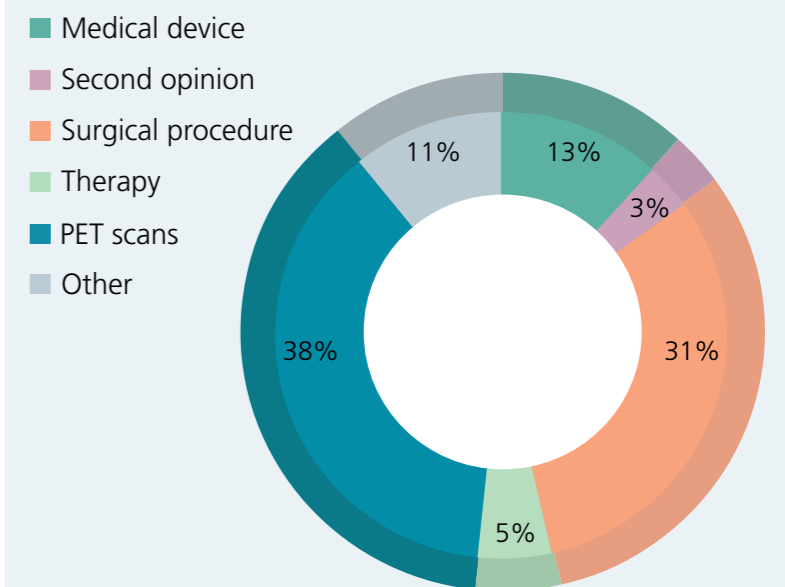
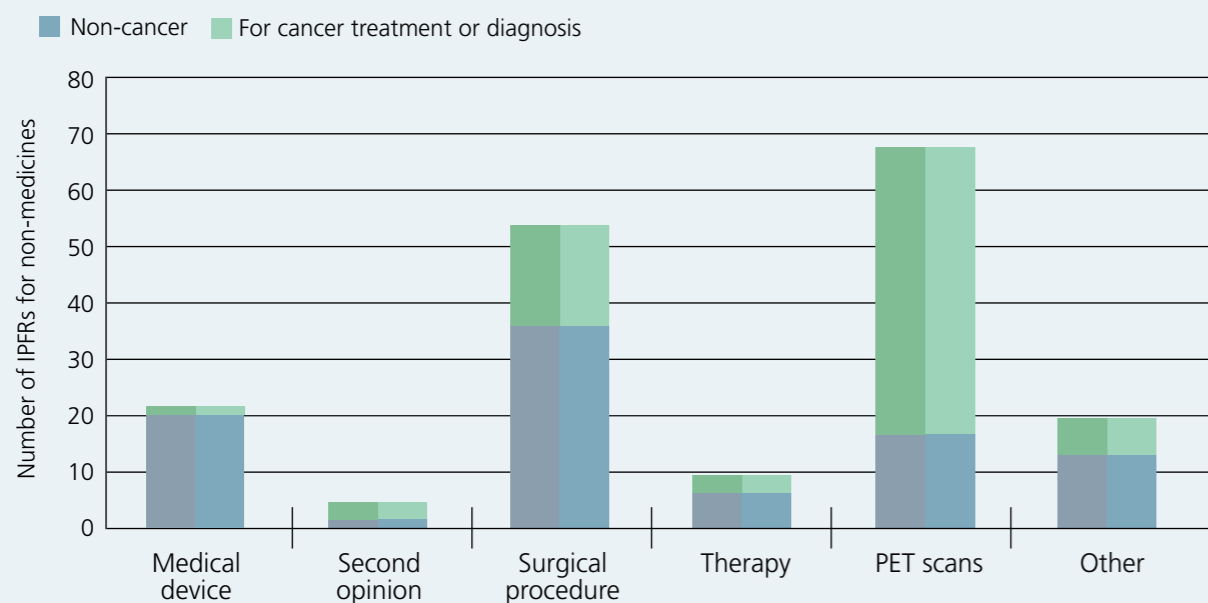


Figure 12 shows the proportion of the types of non-medicine request for cancer and non-cancer conditions. Overall, 47% of non-medicine requests were for cancer interventions. The highest number of non-medicine IPFRs for cancer interventions were for PET scans and for surgical procedures with 49 and 19 requests in 2023–2024, respectively. For non-medicine interventions for other conditions the highest number of IPFRs were for surgical procedures and medical devices, with 36 and 20 requests in 2023–2024, respectively.

Figure 12: Number of IPFRs for non-medicines by intervention type in 2023–2024



In 2023–2024 Health Technology Wales (HTW) continued to support IPFR panels, conducting rapid evidence summaries to provide additional information to support panel decision making. A total of 9 requests for evidence summaries were submitted and HTW produced 5 new summaries. In 2 cases they did not have capacity to produce new summaries within the timeframe requested; however, the panels were provided with summaries that had been conducted for previous IPFRs for the same indication. One of the requests was urgent and HTW sent a previous report with a table of the patient and intervention characteristics for both cases to compare. There were 3 requests for review summaries on functional neurologic disorder assessment and management; the remaining 6 were for differing interventions and indications.

Panel activity

In 2023–2024 Cardiff and Vale UHB panel recruited and trained two new panel members and a Vice Chair. The Cardiff and Vale UHB team have also given IPFR panel training to a cohort of public health speciality registrars.

Cwm Taf Morgannwg UHB have made an effort to recruit deputies for panel members, thus strengthening the panel and ensuring quoracy. The panel still have an issue with lay membership and are seeking to recruit lay members in 2024–2025.

Powys Teaching Health Board has piloted more objective approaches to the assessment of cost effectiveness in their decision making, with input from health economists at AWTTTC. This work is ongoing, with a view to taking a more robust approach to the rapid assessment of cost effectiveness in situations where formal analysis is not available and where information is imperfect.

Swansea Bay University Health Board appointed a new panel Chair and a new Vice Chair. The new Chair and Vice Chair have streamlined processes, including the IPFR process, to manage the volume of requests efficiently. An IPFR pre-meeting has been introduced to discuss cases and identify any additional information that may be required before consideration at the full panel meeting. The pre-meeting also provides opportunity to agree simple prior approval requests, allowing time for detailed discussions of more complex requests at the scheduled meeting and streamlining the process.

The team at Swansea Bay UHB reported that the panel have dealt with some extremely complex cases in the past year, in particular involving continued patient care. Working with the Continuing Healthcare Team in Swansea Bay UHB has provided clarity as to how continued care for complex cases is funded, allowing for such cases to be routed through the correct decision-making process preventing delays and ensuring patient care is not interrupted.

In the coming year Swansea Bay UHB plan to seek panel membership from healthcare professionals who are currently under-represented. There are also plans to improve communication of IPFR decisions with more clarity around the starting and stopping criteria for treatment. Swansea Bay UHB panel will continue to collaborate with other stakeholders to enhance the decision-making process.

IPFR and the One Wales Medicines process

The One Wales Medicines (OW) process was set up in 2015. It enables one decision for all of NHS Wales about access to a medicine, which is usually being used 'off-label', that is not routinely available for a group of patients (a patient 'cohort') who have an unmet clinical need.

AWTTC regularly collects and analyses data from IPFRs across Wales, to look for patient cohorts for particular medicines and conditions. Where there is evidence of a potential cohort coming through IPFR that could be a candidate for OW, the OW team will contact the relevant clinical network or clinical group to ask if they would be interested in pursuing access through the OW process. Healthcare professionals in Wales can also ask for medicines to be considered by the OW process, through their clinical networks or committees.

The One Wales Medicines Assessment Group (OWMAG) considers the evidence on the effectiveness of the medicine and makes a recommendation on the use of the medicine in NHS Wales. A change to the process was made in early 2023 so that all OWMAG recommendations now go to the All Wales Medicines Strategy Group (AWMSG) for endorsement, and then to Welsh Government to be ratified. Therefore, all OW process activity is now reported in the [AWMSG annual report](#).

Ongoing monitoring of IPFR data shows that soon after a positive OW decision is published, IPFRs are no longer submitted for that medicine and condition. This shows that the OW process accelerates equitable patient and clinician access to these medicines across Wales.

As of March 2024, there were 19 published OW decisions, 18 of which were positive recommendations enabling access to medicines for the treatment of patients with conditions where there is an unmet clinical need.

More information on the One Wales Medicines process, and current One Wales decisions, is on the [AWTTC website](#).



Patient outcomes

Of all data collected during 2023–2024, patient outcome data were available for 57 patients, all after requests for medicines that had been approved. This represents outcome data for 14.5% of all IPFRs for the year; a decrease on the 17% of outcomes reported in 2022–2023.

Twenty-five (44%) of the outcomes reported were applications for continued funding of medicines that had been previously approved. The remaining 22 were reported using the IPFR outcome form or by email on request of 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).

Complete information is not reported for all of the outcomes. All outcomes were reported for funded medicines; there were no data reported for non-medicine interventions during 2023–2024. In most cases the patient had started treatment or had received the full course of treatment.

Of the feedback provided, 32 of 48 patients (67%) were reported to have had a complete or partial response to treatment, and 28 of 42 patients (67%) had an improvement in their quality of life.

Best response to treatment



Five patients had received the full course of treatment and in 36 cases treatment was ongoing. In 21 cases treatment had been stopped early. Where reasons had been provided for stopping treatment early, the most common reason was due to disease progression (see infographic). In 3 cases patients did not receive the funded medicine: one patient had responded to their current treatment and did not require the requested medicine; one patient deteriorated and received palliative care instead; and one patient died before the treatment could be provided.

Quality of life following or during treatment



In total, 9 patient deaths were reported, 8 after progression of cancer; 2 patients had maintained their quality of life; and 1 patient reported an improvement in quality of life. One patient experienced disease progression and died without receiving the funded medicine. The remaining 5 patients had died after completing treatment and no further details were provided.

Reasons for stopping treatment



Most IPFRs approved in 2023–2024 for which we have outcome information were associated with evidence of clinical benefit and a maintenance or an improvement in quality of life.

The number of outcomes reported in 2023–2024 is the same as in 2022–2023, representing a fall in the proportion of IPFRs with data reported; the number remains lower than AWTTTC would like. Collecting outcome data is important to monitor and analyse whether a treatment was effective. Most outcome data are submitted with a request for continued funding for treatment. Consequently, most outcome data relate to patients who are benefitting from an

approved medicine. We lack data on one-off treatments, in particular for non-medicines such as surgical procedures or medical devices, for which no outcomes were reported during 2023–2024. We also lack outcomes reported where treatment requests were declined. It is important for the IPFR service to monitor outcomes to give information about the impact of IPFR decisions on patients.

An update to the IPFR database will be made in 2024–2025 to prompt IPFR co-ordinators to request outcome data. We hope that this may improve the number of outcomes reported during 2024–2025.

AWTTTC will work with panels and clinicians to explore new ways to improve outcome reporting.

Quality Assurance Advisory Group

Quality assurance of the IPFR process showed that, overall, outcome measures were at a high level during 2023. On average 97% and 92% of IPFRs reviewed met the assessment criteria for the application and panel processes, respectively; with 88% meeting the decision process criteria.

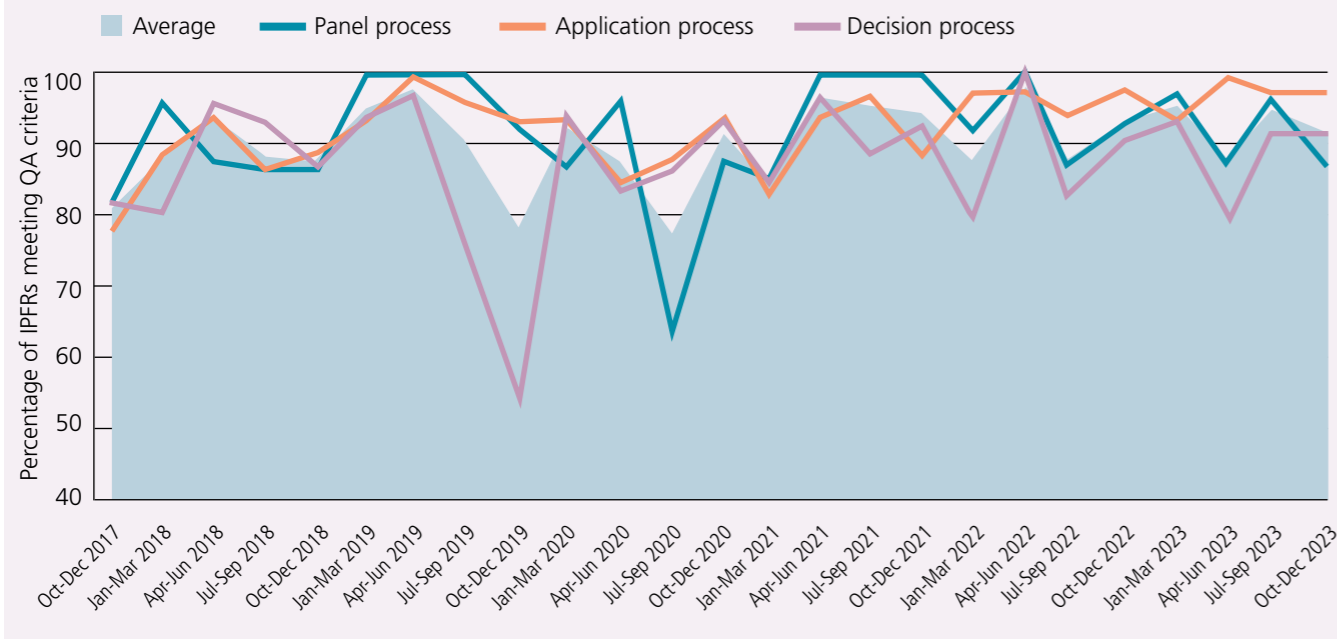
The primary function of the IPFR Quality Assurance Advisory (IPFR QA) Group is to examine and address variation between panels in relation to consistency in the decision-making process. The Group is provided with all paperwork associated with a randomly selected IPFR from each quarter, including the 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. 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 IPFR QA Group are available on the [AWTTTC website](#).

In the latter half of 2023 IPFR QA group members resumed observing IPFR panel meetings; providing feedback to the group and to panels through their quarterly report. One panel is observed every quarter, therefore each panel is observed once every 2 years. In 2023, members observed meetings of the Betsi Cadwaladr UHB panel and the Cardiff and Vale panel. Both panels showed a good level of discussion for the IPFRs considered. Feedback to the panels included advice for the panel Chair to steer discussion in line with IPFR criteria in the policy. Panels were also advised to utilise Health Board formulary pharmacists to confirm medicine costs before the meeting. IPFR QA group members found the experience valuable to provide reassurance that IPFR panel meetings are being conducted in a fair and consistent manner. Observation continues in 2024.

In the year 2023–2024, the Group met four times to assess IPFRs covering the 2023 calendar year. Figure 13 shows the percentage of criteria met for each quarter from October 2017 to December 2023. The percentage of assessments meeting the criteria of all three processes fluctuated between just under 80% to 100%, which corresponds to only a few criteria not being met each quarter. The marked decrease in the percentage of decision process criteria met during Quarter 2 2023 is attributed to clinician and patient letters being sent outside the five-day timeline by two panels.

A detailed report is sent to each panel providing feedback on the IPFR 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 is sent every six months to the Deputy Chief Medical Officer and to the pharmacy and prescribing branch of Welsh Government.

Figure 13: Percentage of IPFRs assessed that met the Quality Assurance process criteria between October 2017 and December 2023



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.

Action points from 2022

In the previous year, the Group advised that IPFR teams should ensure that the documentation given in the submission is sufficient for a case to be considered by a panel, and that the panel should defer a case if there was a consensus that not enough evidence had been submitted to allow robust decision-making. The Group have noted that IPFR teams and panels are increasingly requesting additional input from submitting clinicians when appropriate.

The Group reminded IPFR panels to avoid using out-of-date terminology or ambiguous statements, particularly in their value-for-money discussions. After this reminder, panels have added additional context to discussion records to explain broad or generalised statements.

The Group also advised panels on the importance of covering all the decision-making criteria and documenting discussions in sufficient detail, including those decisions made by Chair's action. Overall improvements to the minutes of meetings were noted by the Group, although there was still room for further improvement by some panels.

The decision rationale provided to the clinician should be timely, clear and concise with sufficient explanation included. Guidance on this was provided at the IPFR workshop in February 2023 and an improvement has subsequently been reported by the Group.

Action points from 2023

- The Group noticed a lack of public health representation for a couple of the panel meetings assessed, although the panel was still deemed quorate. It was acknowledged that attendance by public health representatives had been problematic during the COVID-19 pandemic, but that public health representative attendance should now fully resume.
- Panels were reminded that decision by Chair's action should be reserved for urgent cases only and applications should go to a full panel meeting whenever possible.
- The economic evaluation of some cases and identifying appropriate comparators still 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.
- Panels were reminded that a letter should be sent to the patient in all cases 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.
- Panels should consider the specific clinical presentation of the patient's circumstances in every case. IPFR teams may identify a cohort of patients emerging that could indicate a need for a service or policy change. This should be referred to processes for local service changes, or to AWTTTC for medicines, or HTW for non-medicine interventions.
- The QA Group resumed observation of panel meetings after a temporary suspension during the COVID-19 pandemic; two meetings were observed during 2023.

In 2023

- 100% of cases reviewed met the urgency deadline
- In all cases assessed the IPFR process was being used appropriately
- 100% of clinician letters clearly stated the decision and the rationale behind it

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

Future action points

- The IPFR policy is being revised to ensure that the wording in the policy and associated documentation is clear, consistent and fit for purpose. The IPFR QA Group will make sure 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.

IPFR Workshop

In May 2024, AWTTTC held its seventh IPFR workshop. The annual workshop is a training event for IPFR panel members, health board colleagues involved in the delivery of the IPFR process, clinicians who complete applications and those with an interest in learning more about IPFR.

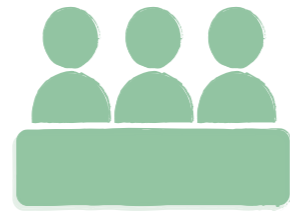
Topics covered during the day included:

- Key themes identified from the quality assurance of the IPFR process over the past year by the IPFR Quality Assurance Group
- Health economics, thresholds and comparative analysis, and how to assess the value of interventions
- Identifying comparators
- Completing IPFR application forms and making an e-submission (clinicians only)

Delegates were given an update on new initiatives at AWTTTC relating to medicines access, including the launch of the All Wales Medicines Strategy Group's new 5-year Strategy, and changes to medicines assessment routes in Wales. In a pre-recorded video, a patient who had received treatment through IPFR shared her experience of the process.



62 attendees with representation from each IPFR panel



Colleagues attended from all Welsh health boards, Velindre Cancer Centre, NHS Wales Joint Commissioning Committee, Public Health Wales, Health Technology Wales and Digital Health and Care Wales

In the second half of the workshop, delegates formed mock 'IPFR panels' and considered example IPFR cases. This encouraged the sharing of experiences across health boards and discussion about the different factors that IPFR panels need to consider when making their decisions. This exercise develops good practice and helps ensure consistency in decision-making across all the IPFR panels in Wales.

Delegates enjoyed the opportunity to network and develop links across health boards and also to find out more about the work of AWTTTC and Health Technology Wales by visiting their display stands throughout the day. Videos and presentations from the 2024 workshop, and from past IPFR workshops, are available on the [AWTTTC website](#).

“Another well planned event – well done all! I particularly enjoyed the patient interview and it reminds us all of the reasons why we make these decisions and the major impact they have on patients.”



“All was useful. I'm planning to sit on an IPFR panel and so it was a good introduction.”

“Good to go through how to complete forms.”



“Great opportunity to meet colleagues across Wales to network and share experiences and good practice.”

“Overall, I thought it was very insightful and good to see how IPFR all fits together for the patient’s journey.”



“I have a much better understanding of the IPFR process and good interactive sessions. Thank you.”



An online IPFR workshop will be held in 2025. It will be open to IPFR panel members and affiliated staff, clinicians and other healthcare professionals.

Summary of the data

Overall, the data for 2023–2024 show:

392

IPFRs were processed across Wales



an increase of 57 compared with 2022–2023

73

(45%) more requests for medicines in 2023–2024 compared with the previous year



77%

Approval rates for non-medicine requests rose to 77% compared with 73% in the previous year



79%

of all IPFRs were approved



the same as during the previous year

81%

Approval rates for medicine requests were down from 85% in 2022–2023 to 81% in 2023–2024



22

The number of IPFRs for non-medicines decreased by 22 (–12%) compared with the previous year

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
JCC	Joint Commissioning Committee
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	When a medicine is used in a different way to what is described in its marketing authorisation (product licence)
OWMAG	One Wales Medicines Assessment Group
PET	Positron emission tomography

Additional note

Where small numbers are involved, we are unable to provide the names of specific treatments as 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. This 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.