



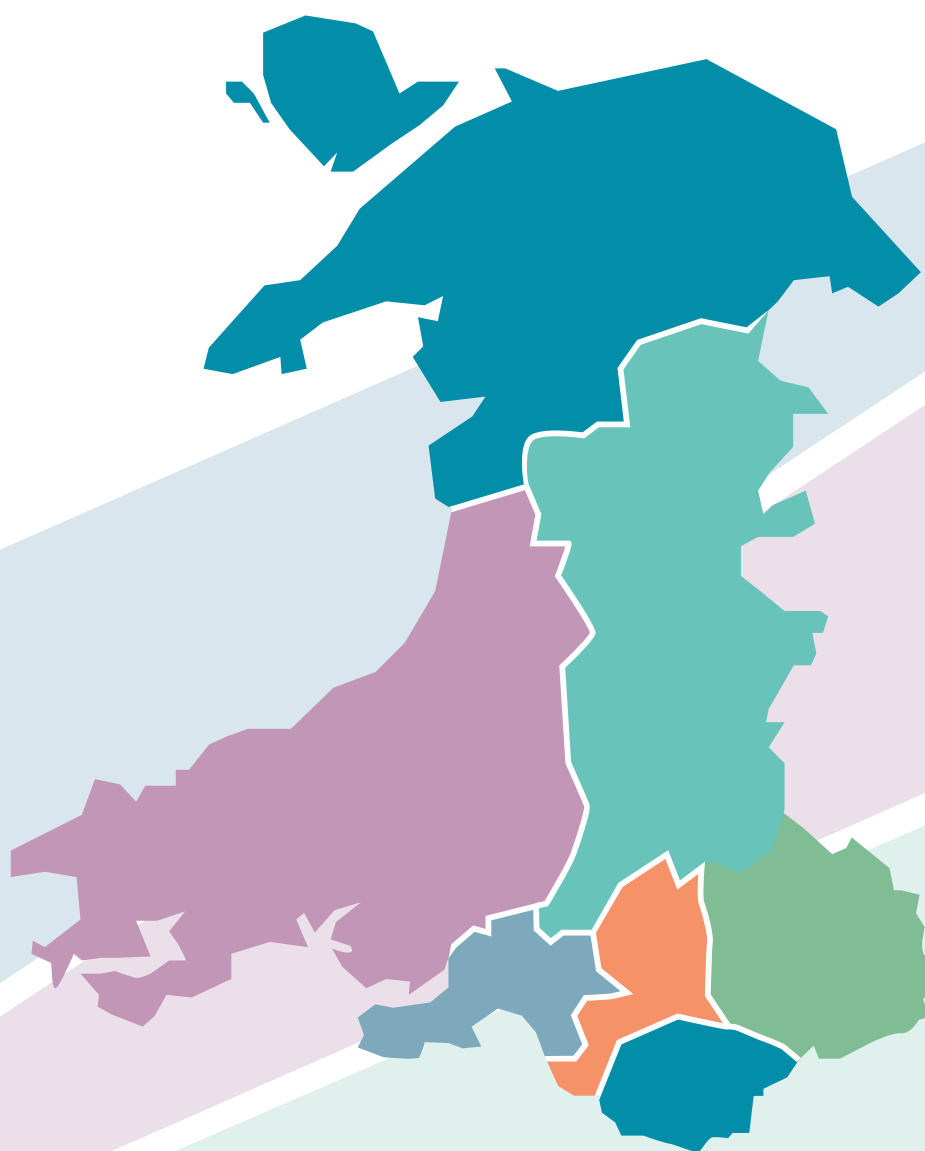
**AWTTC**

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



# Individual Patient Funding Request (IPFR)

## Annual Report 2022-2023



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

# Contents

01	A statement from AW TTC's clinical director	2
02	Executive summary	3
03	Background	4
04	Individual Patient Funding Requests (IPFRs)	5
05	IPFRs for medicines by health board and Welsh Health Specialised Services Committee (WHSSC)	8
06	IPFRs for non-medicines by health board and WHSSC	12
07	Panel activity	16
08	IPFR and the One Wales Medicines process	17
09	Patient outcomes	19
10	Quality Assurance Advisory Group	21
11	IPFR Workshop	25
12	Summary of the data	27
13	Glossary and additional note	28

## AWTTC Clinical Director's statement

Overall 2022-2023 was a busy year for panels, with a total of 335 cases going to panel, a 6% increase on the previous year, and more than has been seen over the last few years. Rates increased for both medicines (requests for cancer treatments) by 5% and non-medicines (requests for positron emission tomography [PET] scans) by 6%. Approval rates are on the up too, hitting 79% in the period 2022-2023.



**Prof James Coulson**  
Clinical Director, AWTTC

AWTTC conducted a recruitment campaign in 2022 to help address the problem of low numbers of lay representatives across the health board panels. The campaign was supported by the health boards in Wales, and used social media and advertising screens in GP practices and hospitals. AWTTC created a page on the AWTTC website that lets people contact AWTTC about joining an IPFR panel or an All Wales Medicines Strategy Group (AWMSG) committee. The campaign generated some interest in joining IPFR panels, but more needs to be done to boost the number of lay members.

The annual IPFR workshop was held at Cardiff City Stadium in February 2023. The event was well attended, a mix of people were present on the day and enjoyed the chance to meet face-to-face and network. Members of the Welsh Health Specialised

Services Committee (WHSSC) gave a challenging talk on a judicial review they had recently been through and shared their learning points with attendees to take back to their panels. A session on "value for money" presented by Health Technology Wales was very practical and several attendees commented on how useful it would be for supporting and documenting their decision-making in future. One clinician shared their experience of the IPFR process in a video interview; it was encouraging to hear that his experiences of the process were overall very positive.

Our Quality Assurance process shows that panels are achieving high rates of concordance with the IPFR policy. It is heartening to see a return to the levels achieved before the COVID 19 pandemic. There is more evidence of panels considering value for money and alternative treatment costs in their decision-making discussions. I have no doubt the excellent session at the 2023 IPFR workshop on value for money will improve this further.

AWTTC's One Wales team had a particularly busy year writing reports for new assessments. These included treatments for conditions of the bowel, blood and lung, and to treat cancer. Most of the assessments were triggered by requests from the service rather than through collection of IPFR cohort data. This may in part be due to the diversity of requests coming through IPFR, but it also shows more awareness by the service of the One Wales Medicines process.

In this annual report we have also captured work being done within individual IPFR panels. Initiatives include: guidance for clinicians completing forms, promoting the collection of outcome data, internal audits and training for new members. This is fantastic to see and we wish all the panels in Wales much success in 2023 and beyond.

## Executive summary

- In 2022–2023 the total number of IPFRs across Wales increased to 335 from 315 in 2021–2022. There were increases in requests for both medicines and for non-medicines by 5% and 6% respectively.
- Powys Teaching Health Board continued to have the highest rate of IPFRs per 100,000 population.
- Similar to previous years, Aneurin Bevan University Health Board had the highest number of medicine IPFRs and WHSSC had the highest number of non-medicine IPFRs.
- The number of IPFRs approved increased from previous years: 79% of all IPFRs were approved in 2022–2023.
- The approval rate for medicine IPFRs increased from 80% in 2021–2022 to 85% in 2022–2023.
- A similar approval rate for non-medicines was seen over the last two years, with 73% approved in 2022–2023 compared with 70% approved in 2021–2022.
- The percentages of patient outcomes reported in 2022–2023 improved from the previous year, from 15% to 17% of all IPFRs considered. Overall 77% of people were reported to have a complete or partial response to treatment, down on last year (83%) and 70% had an improvement in quality of life, again lower than last year (80%).
- Over 90% of IPFRs reviewed by the IPFR Quality Assurance group met the criteria used to assess how well panels are following the IPFR policy. This percentage was attained across all three process areas demonstrating a return to pre COVID-19 pandemic levels.
- The IPFR workshop was held at Cardiff City Stadium in February 2023 and was well received. Videos and presentations from the workshop can be viewed on the AWTTC website.
- Eight medicines were assessed through the One Wales Medicines process; six reviews were conducted and one medicine was retired from the work programme because it is now included within national guidelines. All One Wales decisions are displayed on the AWTTC website.

Background

A comprehensive range of NHS healthcare services are routinely provided across health boards in Wales. The Welsh Health Specialised Services Committee (WHSSC), working on behalf of the seven health boards in Wales, commissions specialised services at a national level. However, each year, the health boards and WHSSC 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 WHSSC 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 could 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 [AWTTC website](#).

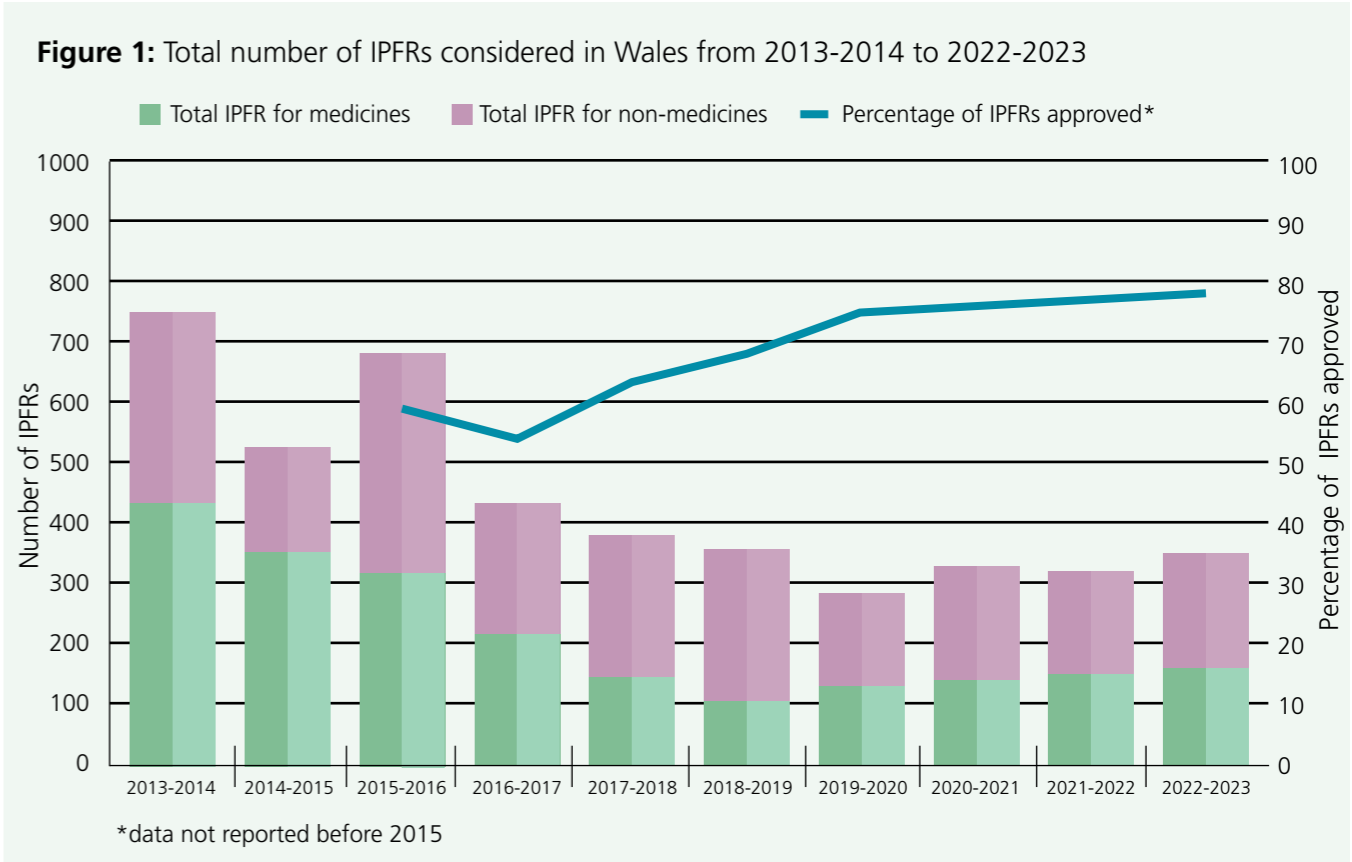
AWTTC supports the IPFR service in Wales by:

- development and updating of the IPFR database;
- audit and maintenance of the quality and desired level of service;
- identification of cohorts and medicines for the One Wales Medicines process; and
- hosting an annual workshop and training event for panel members and people with an interest in IPFR.

Individual Patient Funding Requests

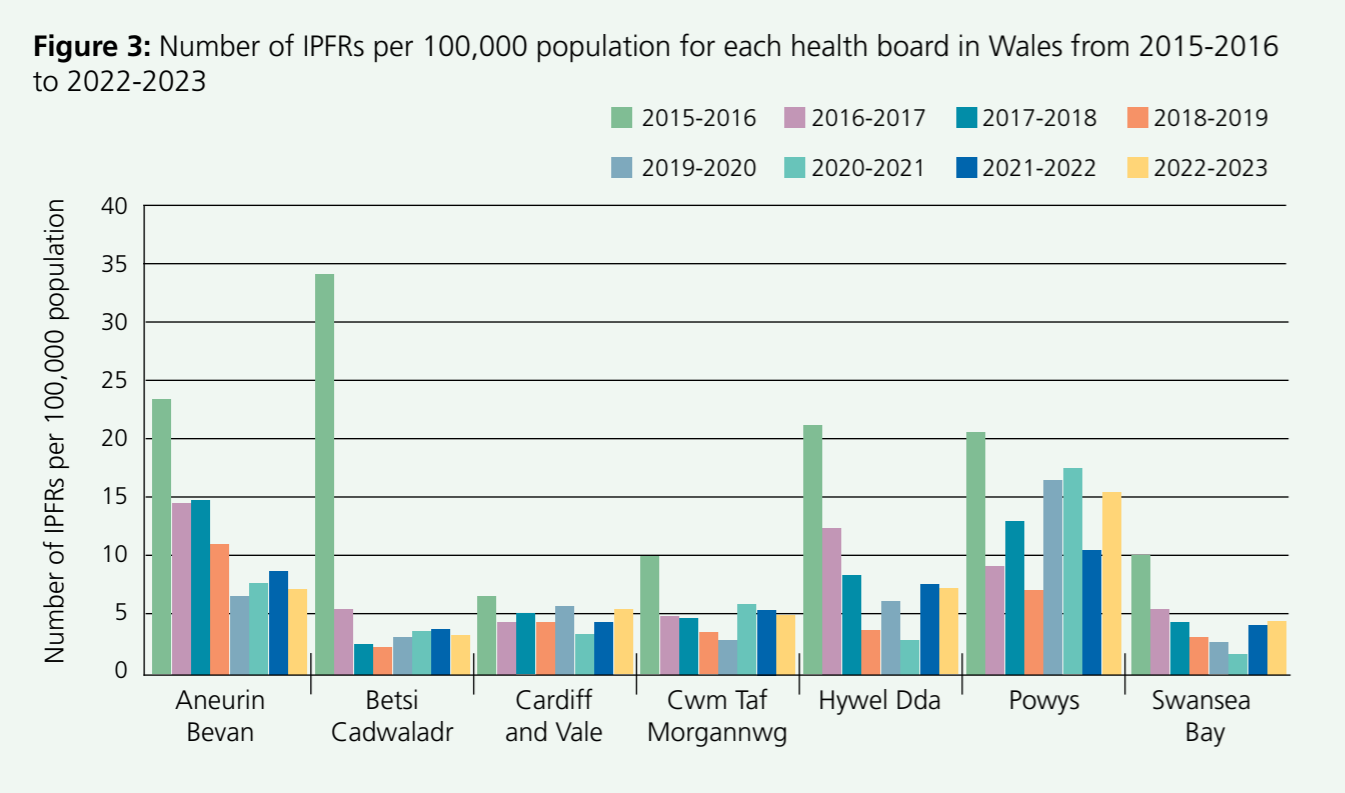
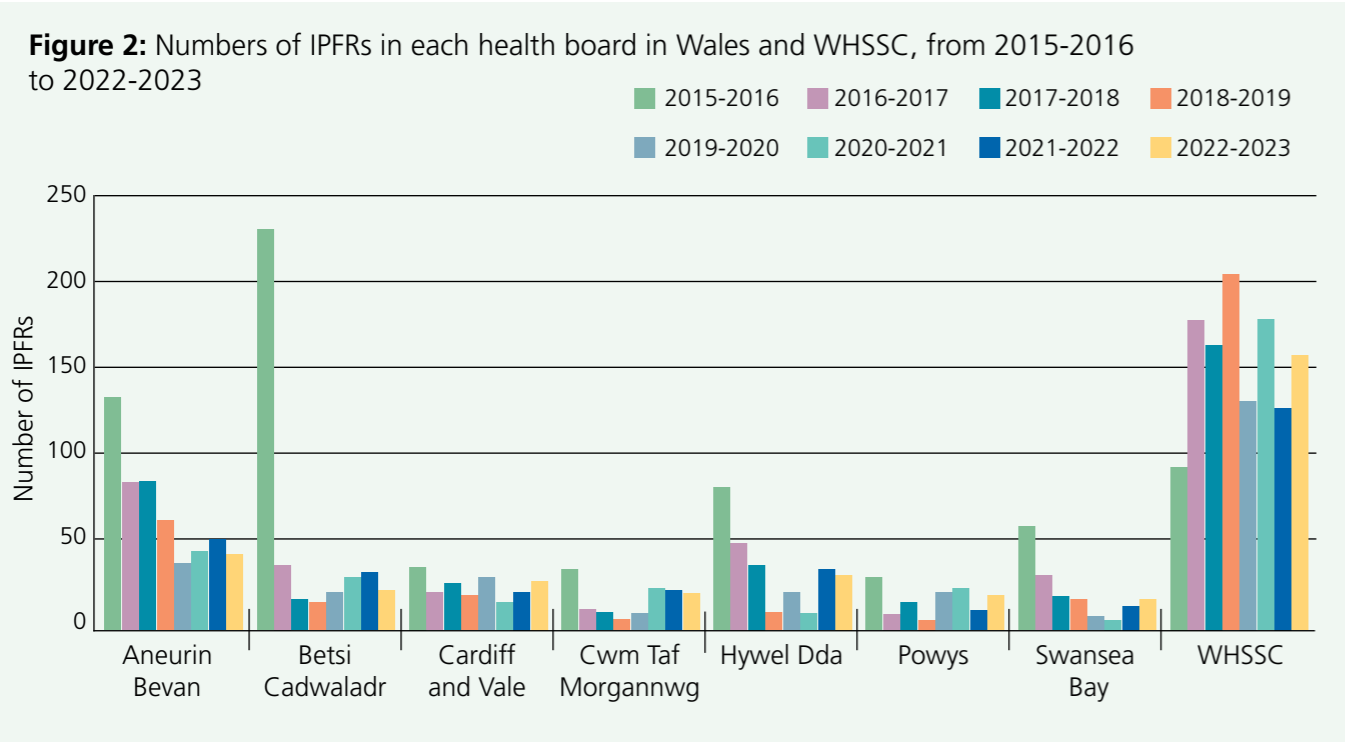
**Between 1 April 2022 and 31 March 2023, health boards in Wales and WHSSC considered a total of 335 IPFRs. This is an increase compared with 2021–2022 when a total of 315 IPFRs were considered (Figure 1).**

Of the 335 IPFRs, 161 were for medicines and 181 were for non-medicines, of these there were 7 requests for both medicines and non-medicines. In 2022–2023, the numbers of requests for both medicines and non-medicines increased, compared with 2021–2022.



The approval rate of all IPFRs during 2022–2023 increased to 79%, from 74% or 75% during the previous three years. The approval rate data were not reported for the years before 2015 so are not included on the graph.

The increase in total IPFRs was not seen across all health boards in Wales. The numbers of IPFRs considered by each panel over the last eight years are shown in Figure 2. Three panels showed an overall increase in IPFRs in 2022/2023, and four panels showed slight decreases. The WHSSC panel reported the most marked increase with 21 more IPFRs considered during 2022-2023 when compared with 2021-2022.



The rate of IPFRs per 100,000 population for each health board during 2022–2023 ranges from 3 to 16 (see Figure 3). Powys Teaching Health Board still had the highest rate of IPFRs per 100,000 population in 2022–2023 and also the largest increase in rate from last year by an additional 5 IPFRs per 100,000. This is not unexpected as Powys commissions services from both Welsh and English providers. Cardiff and Vale University Health Board and Swansea Bay University Health Board both showed the next largest increase (increase of 1 IPFR per 100,000 each). However, the numbers are low for both of these panels and so small numerical differences translate to larger difference in rates.

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 number of requests did not differ greatly from the previous year with 45 requests for continuation of funding; 40 for medicines and 5 for non-medicines. Most requests (87%) were approved.

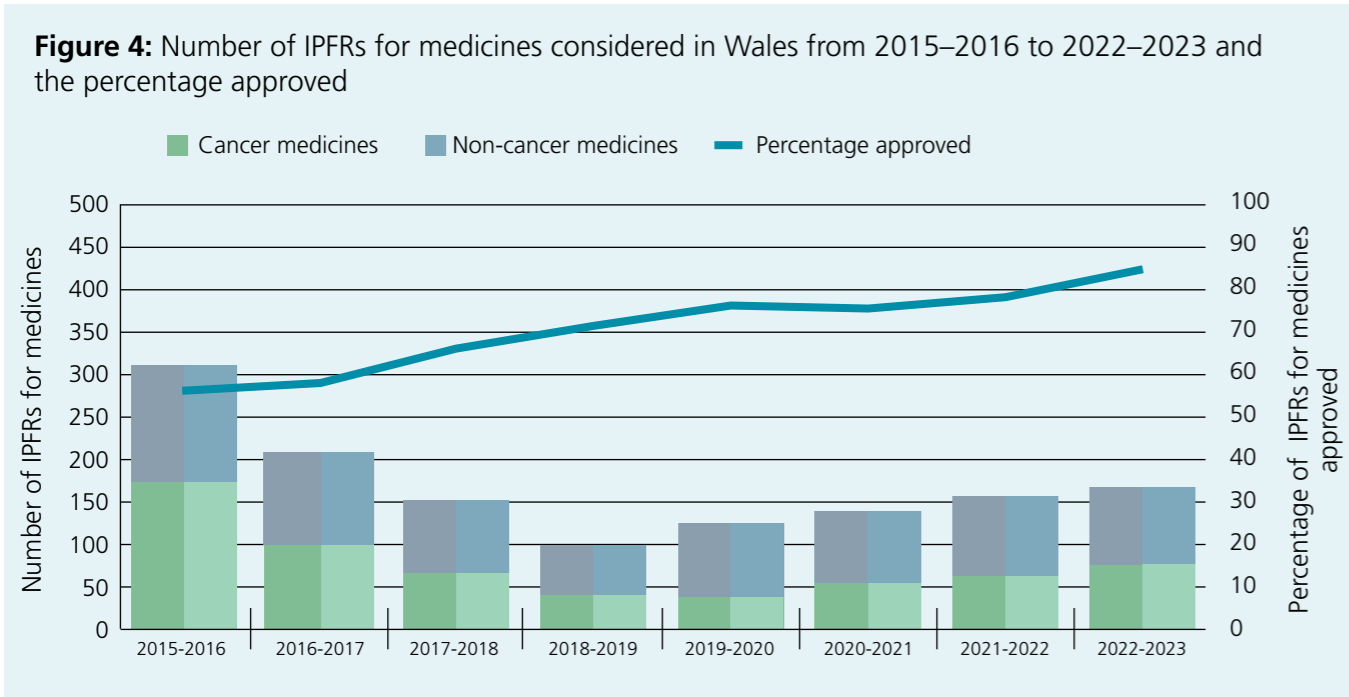
Independent reviews

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. In 2022–2023 we are pleased to report that no reviews were undertaken.

# IPFRs for medicines by health board and Welsh Health Specialised Services Committee (WHSSC)

During 2022–2023 the number of IPFRs for medicines increased to 161, compared with 153 during 2021–2022 (Figure 4). IPFRs for medicines have increased each year since 2018–2019.

A total of 137 IPFRs for medicines were approved, 23 were not approved and 1 IPFR was deferred. The approval rate of IPFRs for medicines was 86%, an increase from 80% in 2021–2022.



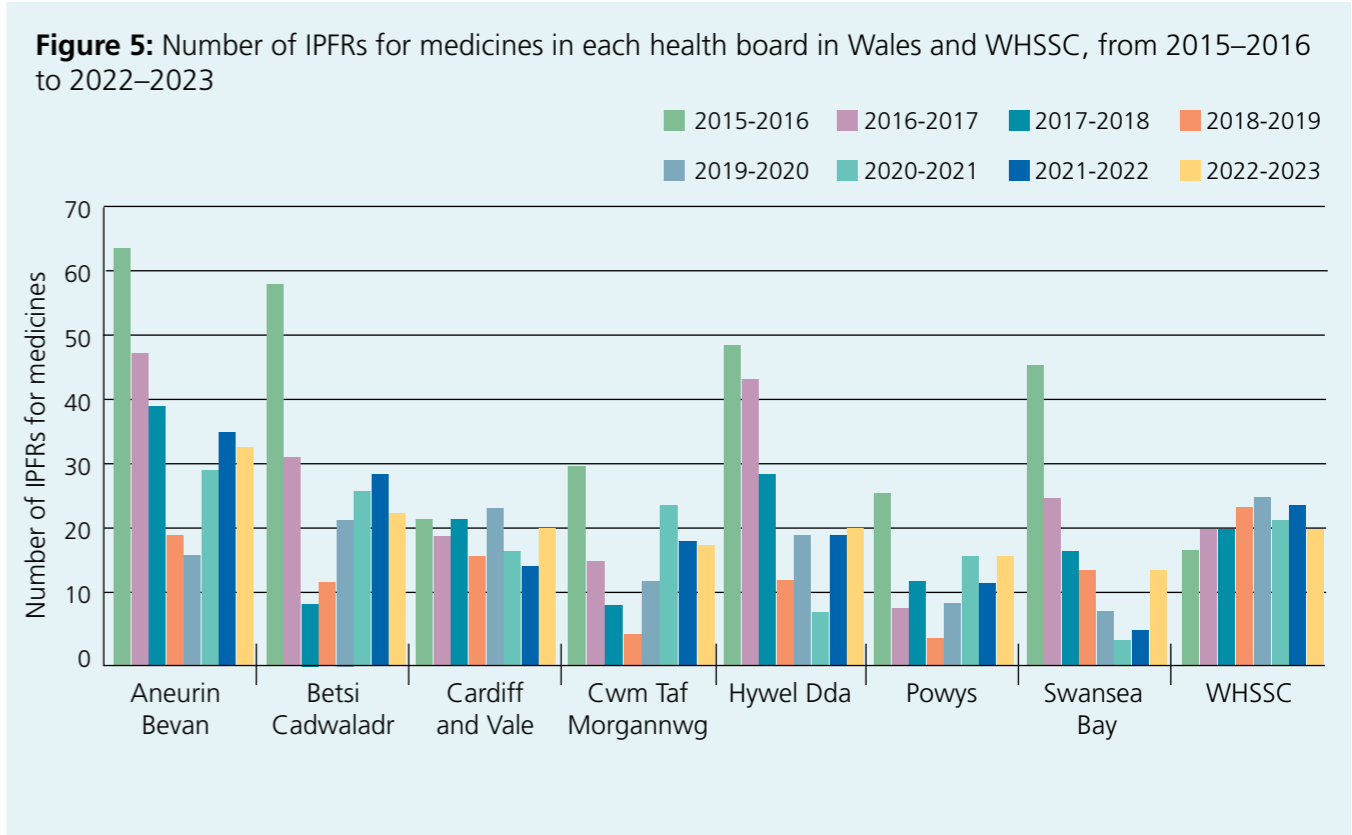
- IPFRs for use of a medicine in Wales happen for three main reasons:
- Advice in relation to a licensed indication for that medicine is not available from the All Wales Medicines Strategy Group (AWMSG) or the National Institute for Health and Care Excellence (NICE).
  - AWMSG or NICE has given advice, 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).

The mean annual number of IPFRs for medicines across all health boards reduced significantly year on year from 41 in 2015–2016 to a low of 11 in 2018–2019. Since 2018–2019 the mean annual number of IPFRs for medicines has increased annually to 20 in 2022–2023.

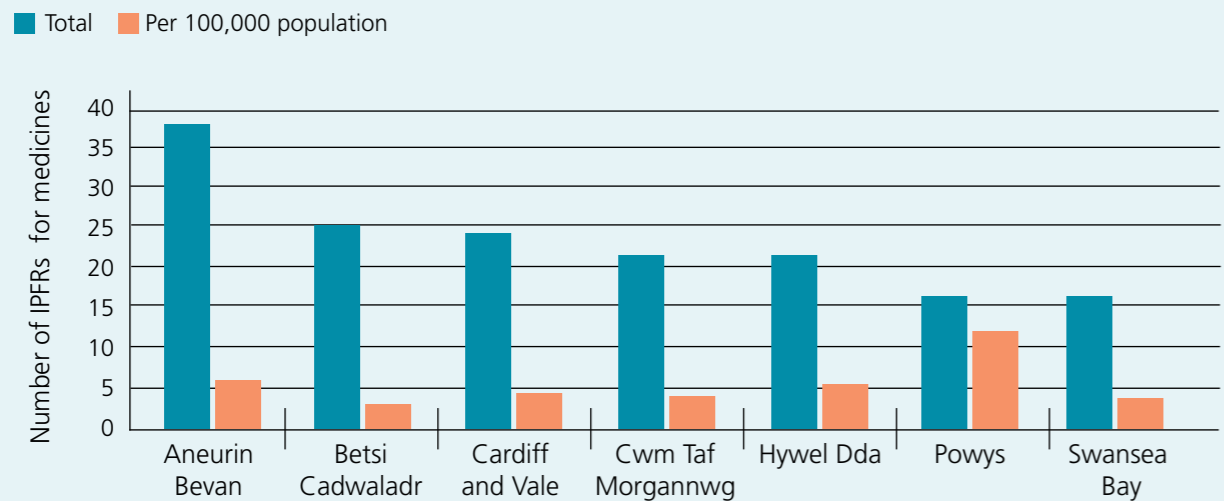
The fall in requests from their peak in 2015–2016 is thought to be due to a better awareness of the most appropriate routes for accessing medicines in Wales. Also, IPFRs were no longer submitted for certain indications after a positive One Wales Medicines decision was published. It is possible that the continued small increase in IPFRs for medicines since 2019–2020 is linked to the COVID-19 pandemic; in particular to avoid hospital attendance for routine drug administration, especially for immunosuppressed patients. If this is the case, we would expect to see medicine requests fall to pre-pandemic rates in the coming years.

During 2022–2023, the number of IPFRs for medicines to treat cancer was 73, an increase from 63 during 2021–2022 (Figure 4). IPFRs for other medicines (non-cancer) decreased slightly to 88, compared with 90 during 2021–2022.

Figure 5 shows the numbers of IPFRs for medicines by health board and WHSSC over the past eight years. Of the 161 IPFRs during 2022–2023, Aneurin Bevan University Health Board had the highest number (32 requests), followed by Betsi Cadwaladr University Health Board with 23; and WHSSC, Cardiff & Vale University Health Board and Hywel Dda University Health Board all had 20 requests each.



**Figure 6:** Numbers of IPFRs for medicines and per 100,000 population for each health board in Wales in 2022–2023



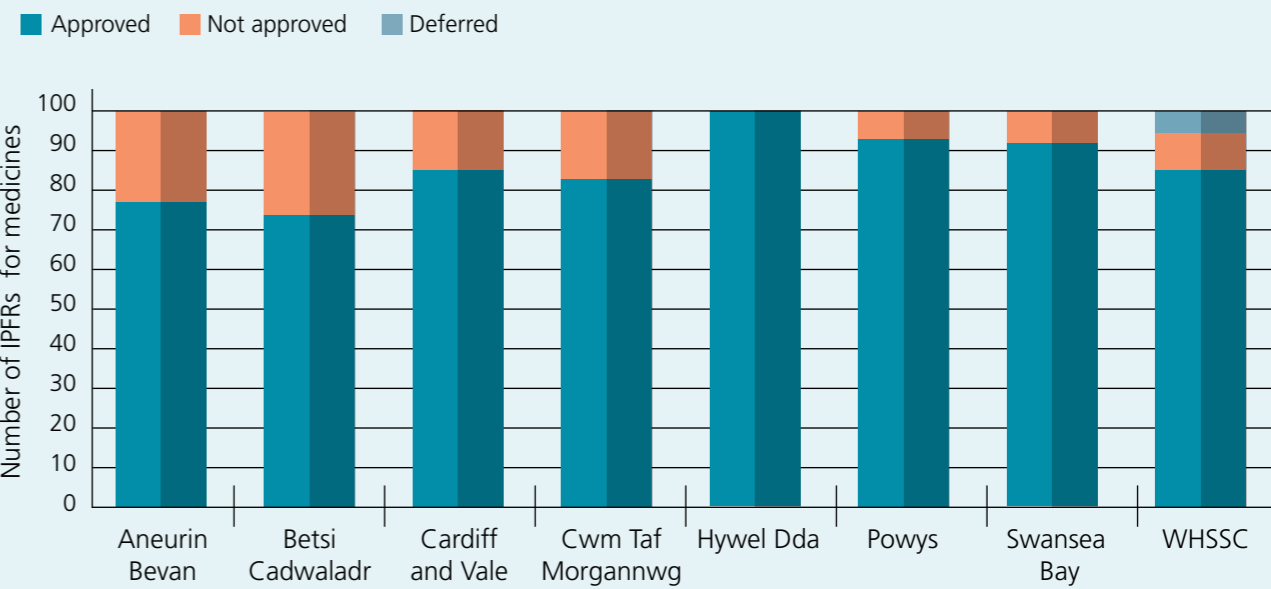
The numbers of IPFRs for medicines vary across the health boards. During 2022–2023, three health boards showed slight decreases in IPFRs for medicines compared with 2021–2022, and two health boards showed a slight increase. Two health boards showed bigger increases in IPFRs: Cardiff and Vale University Health Board IPFRs increased to 20 (from 14 in 2021–2022), and Swansea Bay IPFRs increased to 14 (from 5 in 2022–2023). IPFRs for WHSSC decreased slightly to 20 (from 23 in 2021–2022).

Figure 6 shows the rates of IPFRs for medicines per 100,000 population for each health board in Wales during 2022–2023. IPFRs for medicines received by WHSSC 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 4 per 100,000 in Betsi Cadwaladr University Health Board and Swansea Bay University Health Board to 12 per 100,000 in Powys Teaching Health Board.

During 2022–2023 the percentage of IPFRs for medicines approved by each health board and WHSSC ranged from 74% to 100% (Figure 7). Hywel Dda University Health Board was the only health board to approve 100% of IPFRs for medicines in 2022–2023. Five health boards and WHSSC approved 80% or more of IPFRs for medicines.

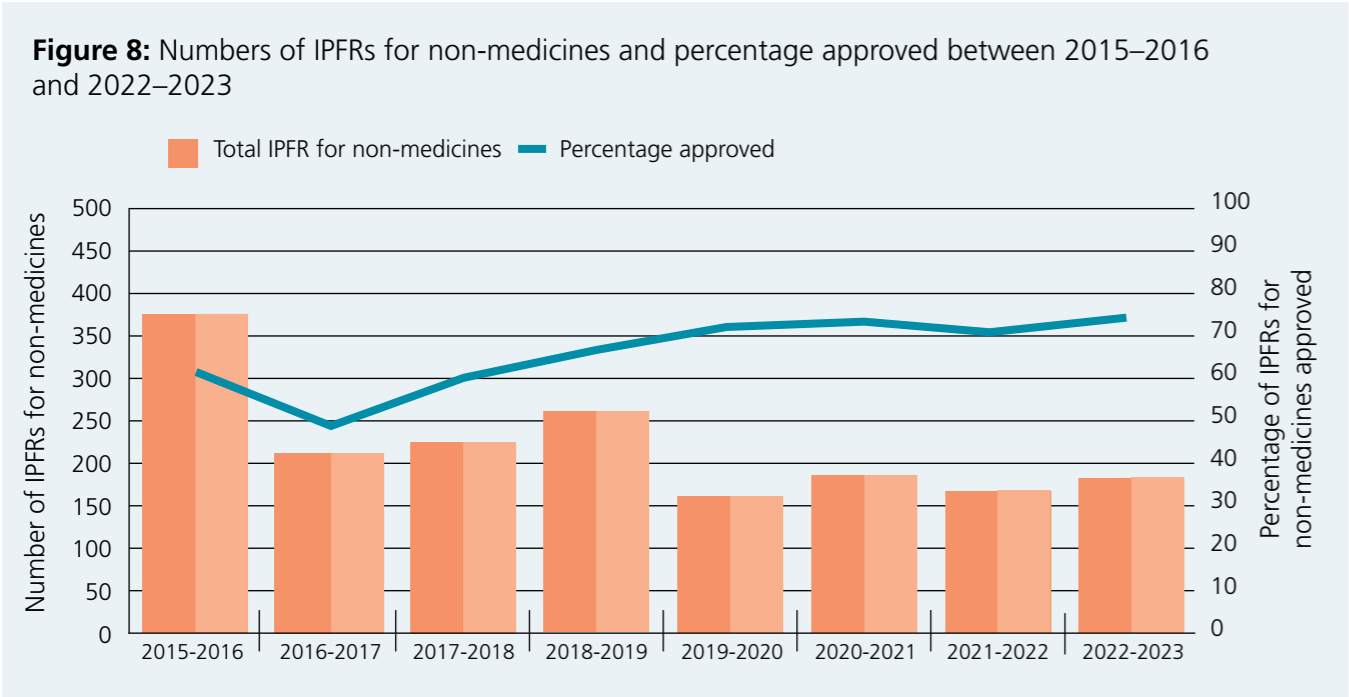
Approval rates for IPFRs for medicines varied between health boards. Differences in the quality and appropriateness of requests affects the approval rate. It is difficult to compare them directly because the overall numbers of IPFRs for medicines were small for some health boards. A small change in the number approved can markedly affect the percentage approval rate.

**Figure 7:** Percentage of IPFRs for medicines approved and not approved for each health board in Wales and WHSSC in 2022–2023



# IPFRs for non-medicines by health board and WHSSC

During 2022–2023 the numbers of IPFRs for non-medicines increased to 181, compared with 171 for 2021–2022 (Figure 8). The rate of approvals of non-medicine IPFRs during 2022–2023 was 73%, slightly higher than the previous period. During 2022–2023, 133 IPFRs for non-medicines were approved, 44 were not approved and 4 were deferred.

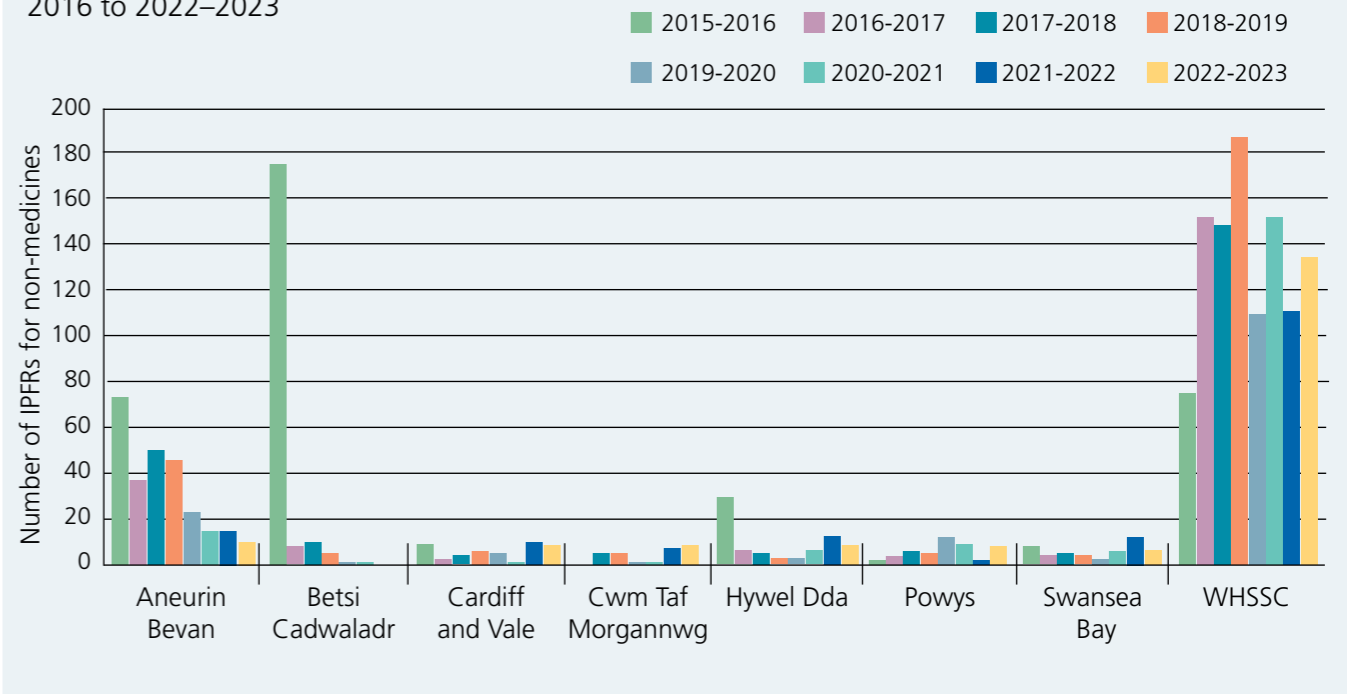


The number of non-medicine IPFRs has fluctuated slightly over the past four years, ranging from 171 to 190. There has been little change in the percentages of non-medicine IPFRs that were approved which ranges between 70% and 73%.

During 2022–2023, WHSSC considered most of the non-medicine IPFRs (n = 137), as in most previous years (Figure 9). The number increased from 115 IPFRs considered by WHSSC during 2021–2022, which was thought to be lower than usual because of fewer requests for positron emission tomography (PET) scans. The increase in non-medicine IPFRs considered by WHSSC during 2022–2023 is driven by more requests for PET scans, which increased to 48, from 34 during 2021–2022.

Four health boards had a decrease in non-medicine IPFRs; two health boards had an increase. Betsi Cadwaladr University Health Board had no IPFRs for non-medicines, as was the case in 2021–2022. For all health boards, the numbers of non-medicine requests are low, and any changes are unlikely to be significant.

**Figure 9:** Number of IPFRs for non-medicines in each health board in Wales and WHSSC, from 2015–2016 to 2022–2023



**Figure 10:** Numbers of IPFRs for non-medicines and per 100,000 population for each health board in Wales in 2022–2023

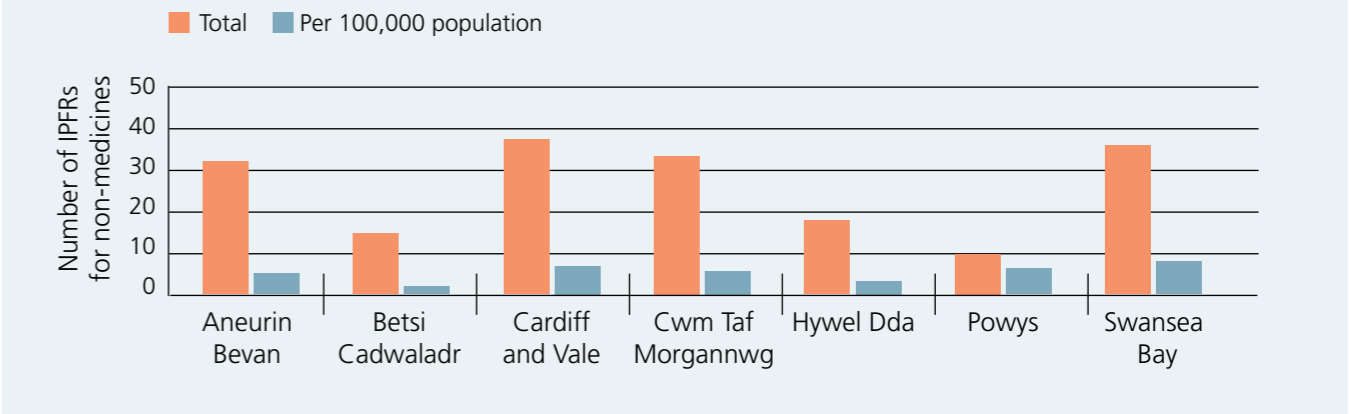
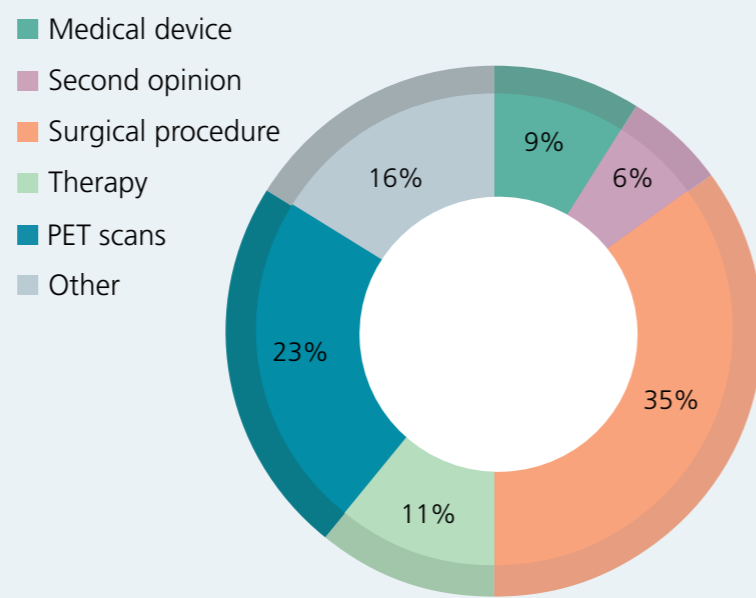


Figure 10 shows the numbers of non-medicine IPFRs and rate per 100,000 population for each health board in Wales. All WHSSC non-medicine IPFRs have been added to the appropriate local panel for each health board. The rate of non-medicine IPFRs per 100,000 population is similar across most health boards, and ranges from 2 in Betsi Cadwaladr University Health Board to 9.5 in Swansea Bay University Health Board.

The types of non-medicine interventions requested through IPFR are shown in Figure 11. After a decrease during 2021–2022 with only 34 IPFRs (20%) for PET scans, during 2022–2023 IPFRs for PET scans increased to 48 (27%).

WHSSC updated its [PET commissioning policy](#) in April 2023 to add new indications: gastric cancer; lymphoma; recurrence of oesophago-gastric tumours; idiopathic inflammatory myopathies; and rheumatological conditions.

**Figure 11:** Percentages of non-medicine IPFRs by type in 2022–2023



The greatest number of non-medicine IPFRs were for surgical procedures (73 requests; 40%). The number of IPFRs for *in vitro* fertilisation (IVF) increased again, from 11 (6%) during 2021–2022 to 23 (13%) during 2022–2023. This is likely in part due to a backlog in referrals as a result of COVID-19 and patients falling outside of policy criteria. IPFRs for cytoreductive surgery and hyperthermic intraperitoneal chemotherapy (HIPEC) during 2022–2023 showed a small increase over the previous year to 10 requests (6%). There were 7 IPFRs (4%) for stereotactic radiosurgery for liver and colon cancers during 2022–2023, and 5 IPFRs for microprocessor controlled prosthetic knees. No IPFRs for prosthetic knees were received during 2021–2022, which might have been due to WHSSC's publication of a new policy in December 2021. The 5 requests during 2022–2023 were for patients who did not meet the criteria for funding under the new policy.

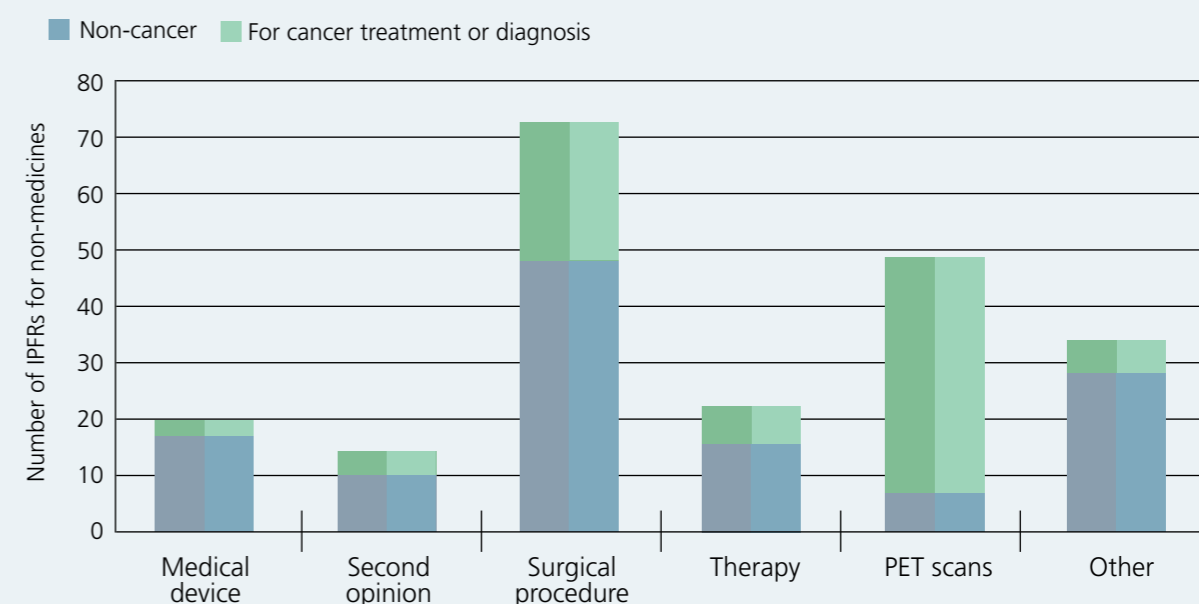
IPFRs for a second opinion during 2022–2023 decreased to 13 (7%) from 21 (11%) during 2021–2022. Of these 13 IPFRs for a second opinion, almost half were for functional neurological disorders. Functional neurological disorders accounted for 10 (6%) of all non-medicine IPFRs in 2022–2023, compared with 2 (1%) during 2021–2022.

During 2022–2023, 83 (46%) of all non-medicine IPFRs were for cancer treatment or diagnosis. Figure 12 shows the number of IPFRs by intervention type for cancer and non-cancer treatment or diagnosis. Around half of the 83 cancer-related IPFRs were for PET scans: 41 in 2022–2023, an increase from 25 during 2021–2022. Surgical procedures were the next most requested IPFRs for non-medicine treatment or diagnosis for cancer, with 24 requests during 2022–2023. Of these 24 requests, the most common surgical procedure requested was for cytoreductive surgery and HIPEC (n = 10).

Of the IPFRs for interventions not for cancer treatment or diagnosis, most were requests for surgical procedures (n = 49). Only 2 of 20 IPFRs for medical devices were for cancer treatment or diagnosis. Of the 13 IPFRs for second opinions, only 3 were for cancer treatment or diagnosis.

Health Technology Wales (HTW) continued to produce non-medicine evidence summaries when requested by IPFR teams to support their decision-making. Thirteen requests for summaries were made during 2022–2023. HTW produced 6 new summaries for panels and provided 4 summaries that had already been produced. Two requests for summaries were declined, and one request was cancelled because it was no longer needed.

**Figure 12:** Numbers of IPFRs for non-medicines by intervention type in 2022–2023



## Panel activity

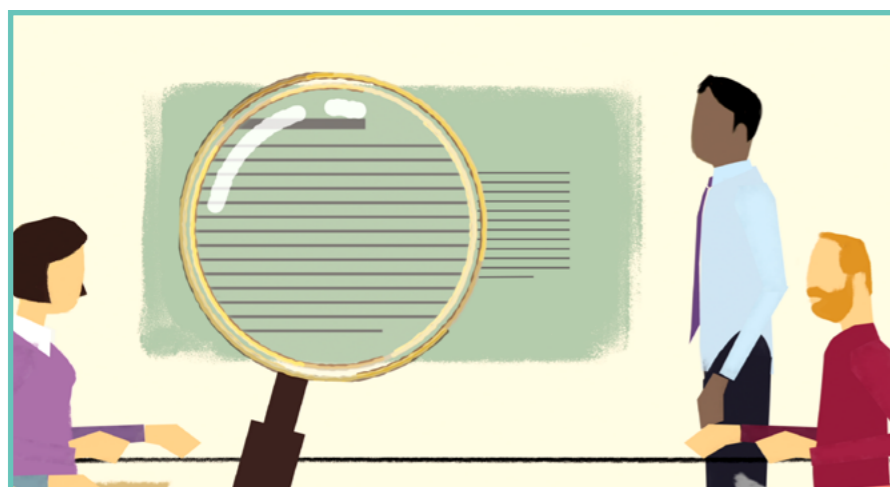
**This year we report on the local activities of IPFR teams who have been busy in 2022-23 providing training, recruiting members and reviewing internal processes.**

In 2022-2023 Cardiff and Vale University Health Board recruited and trained four new panel members, Betsi Cadwaladr University Health Board recruited two new members and Powys Teaching Health Board recruited one new lay member. Cardiff and Vale University Health Board and Swansea Bay University Health Board have both developed and provided training for new members. Cardiff and Vale University Health Board held a training session for Public Health specialist registrars and Swansea Bay University Health Board developed new training materials for colleagues who complete IPFR application forms. Following the IPFR Workshop Betsi Cadwaladr University Health Board held face-to-face cascade training to run through the programme and discuss key messages with panel members who had been unable to attend.

Swansea Bay University Health Board developed a checklist to accompany the IPFR application form to help applicants provide all essential information and avoid the need for forms to be returned as incomplete. Powys Teaching Health Board is promoting the use of the IPFR outcomes form to provide clinical feedback; the response has been positive overall.

Cardiff and Vale University Health Board received substantial assurance in an internal audit of their IPFR systems and processes against the All Wales IPFR Policy.

In 2022-2023 WHSSC started to use IPFR data to inform policy development. Trends in IPFRs are considered by the WHSSC Policy Development Group on a regular basis.



## IPFR and the One Wales Medicines process

The One Wales Medicines process was set up in 2015. It enables **one** decision for all of NHS Wales about access to a medicine that is not routinely available for a group of patients (a patient 'cohort') who have an unmet clinical need. This includes medicines that are used 'off-label' and also licensed medicines, where it is a chance to collect more data before health technology assessment.

AWTTC regularly collects and analyses data from IPFRs across Wales, to look for patient cohorts for particular medicines and conditions. Healthcare professionals in Wales can also ask for medicines to be considered by the One Wales Medicines 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.

The One Wales Medicines process changed in 2022-2023. Instead of a recommendation being endorsed by the Chief Executive Management team, from January 2023, all of OWMAG's recommendations go to AWMMSG for endorsement, and then to Welsh Government to be ratified.

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

An animated video about the One Wales Medicines process was launched in October 2022. [English and Welsh subtitled versions](#) are on the [AWTTC You Tube channel](#) and the [AWTTC website](#).

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



One Wales Medicines Process activity in 2022–2023

As of 2022/2023, there were 17 One Wales recommendations enabling access to medicines for the treatment of patients with conditions where there is an unmet clinical need



Patient outcomes

Of all data collected during 2022–2023, patient outcome data were available for 56 patients, and all after requests for an intervention that had been approved. This represents outcome data for 17% of all IPFRs for the year; a slight increase on the 15% of outcomes reported in 2021–2022.

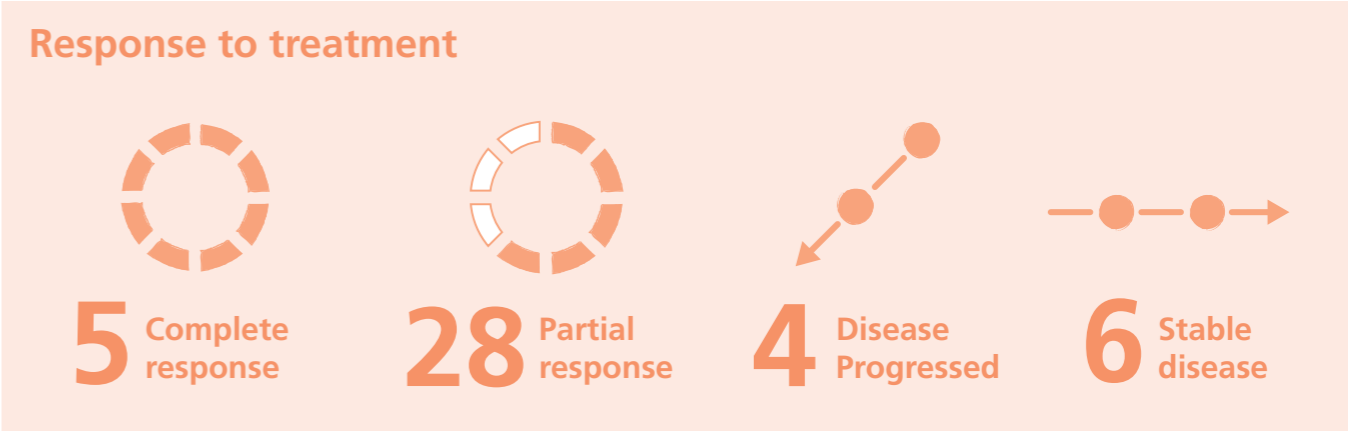
Thirty-three of the outcomes reported were applications for continued funding of medicines that had been previously approved. Three were reported after funding of non-medicines. The remaining 20 were reported using the IPFR outcome form or by email on request of the IPFR teams.

The outcome data give an overview of information provided about:

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

Note that complete information is not reported for all of the outcomes. Most outcomes (95%) were reported for funded medicines, and just three for funded non-medicines. All patients whose outcomes were reported had started treatment; most received the full course of funded treatment except for 7 patients for whom treatment was discontinued.

Of the feedback provided 33 of 43 patients (77%) were reported to have had a complete or partial response to treatment and 16 of 23 patients (70%) had an improvement in quality of life. No reported outcomes mentioned a delay in treatment.



Treatment was discontinued in 7 cases: 4 patients had disease progression; 1 patient chose to discontinue treatment; 1 patient had to stop treatment because the production of the medicine was discontinued and it was no longer available; 1 patient died when still receiving treatment. In total 7 patient deaths were reported. Six patients died after progression of cancer; for 1 patient the treatment had stabilised the disease and maintained their quality of life, extending life from days to weeks. Another patient who experienced cancer progression and died reported that

their quality of life was maintained whilst on treatment. The remaining 5 patients had died after completing treatment and no further details were provided.

### Quality of life following treatment

**16**  
Improved



**5**  
Maintained



**2**  
Reduced



Most IPFRs approved in 2022–2023 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 cases for which outcome data are available was higher than the previous year, but remains low overall.

**56** patients received treatment  
**33** continue to receive treatment

### Reasons for stopping treatment

**1**  
Death

**4**  
Disease progression

**1**  
Medicine no longer available

**1**  
Patient choice

Although the number of outcomes reported has improved slightly in 2022–2023 from the previous year, 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. We also lack outcomes reported where treatment requests were declined. It is important for the IPFR service to monitor outcomes to give information on the impact of decisions on patients.

In 2022-2023 AWTTTC talked to the IPFR co-ordinators in Wales to establish how and when outcome data are requested. Good practice to promote data collection was highlighted by the QA group and shared across panels. The IPFR database is currently being developed to prompt users to request outcome data, and we plan to cover this at the next IPFR workshop in 2024. AWTTTC anticipate that these measures will improve the reporting of outcomes in future.

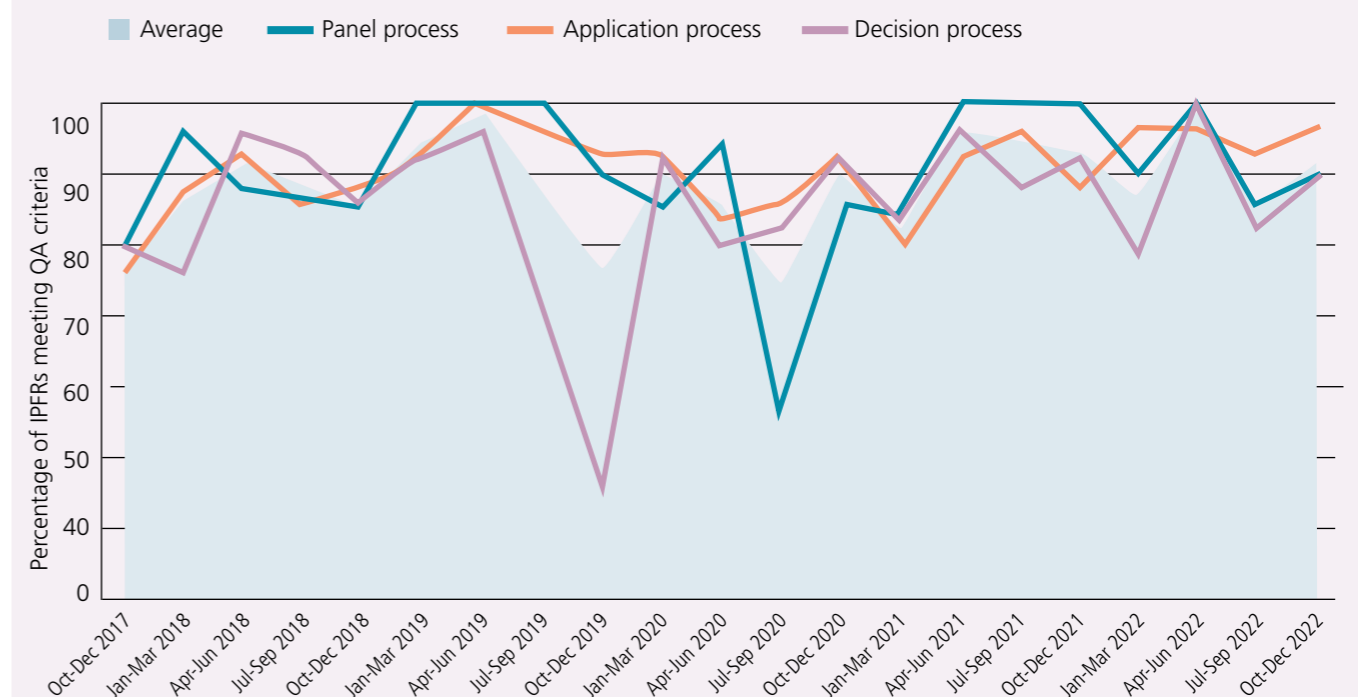
## Quality Assurance Advisory Group

**Quality assurance of the IPFR process showed that, overall, outcome measures were at a high level during 2022. On average, over 90% of IPFRs reviewed met the assessment criteria in all three process areas and demonstrated that the expected high standards of service have returned after disruption caused by the COVID-19 pandemic.**

The primary function of the IPFR Quality Assurance Advisory Group is to examine and address variation between panels in relation to consistency in decision-making. The Group is given all paperwork associated with a randomly selected IPFR from each quarter (3-month period) including the application form, supporting documentation and correspondence with the applicant clinician. All documents are fully redacted by the local IPFR team to remove patient identifying details before sending to AWTTTC. The group assesses aspects of the application process, the panel process and decision process against pre-defined criteria and in line with the IPFR policy.

To align with IPFR panel membership, a second lay member was appointed to the Group this year. The Group also provided comments to WHSSC and the IPFR Policy Implementation Group on the draft update of the NHS Wales IPFR Policy. The Terms of Reference for the Group are available on the [IPFR pages of the AWTTTC website](#).

**Figure 13:** Percentage of IPFRs assessed meeting the Quality Assurance process criteria between October 2017 and December 2022



During 2022-2023, the Group met four times to assess IPFRs covering the 2022 calendar year. Figure 13 shows the percentage of criteria met for each quarter from October 2017 to December 2022. The application process showed sustained improvement in 2022 compared with previous years with over 90% of IPFRs assessed meeting these criteria each quarter. The percentage of assessments meeting the criteria for the panel and the decision processes fluctuated from between just under 80% to 100% which corresponds to only a few criteria not being met each quarter.

Each panel is sent a detailed report giving feedback on the IPFR application form 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.

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 2021

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. Some panels are now documenting when insufficient evidence has been provided and requesting additional information where appropriate, or deferring cases if the information is not forthcoming.

Panels were encouraged to request evidence summaries from Health Technology Wales to support non-medicine requests. This service was used by panels to support ten IPFRs in 2022-2023.

Many panels did not have lay members. A recruitment drive co-ordinated by AW TTC in 2022 resulted in some expressions of interest in this role from members of the public.

### Advert used for screens in GP surgeries and hospital areas to advertise lay recruitment



### Action points from 2022

- All IPFR teams should make sure that documentation is sufficient for a case to be considered by a panel. Panels should defer cases where there is consensus that not enough evidence has been submitted to allow robust decision-making and request further information from the submitting clinician.
- Panels should ensure that quoracy criteria, outlined in the terms of reference in the NHS Wales IPFR Policy, are met. Health board panels are required to send a representative to WHSSC IPFR panel meetings to ensure quoracy of this panel.
- There is more evidence of panels considering value for money and alternative treatment costs in their decision-making discussions but there is still room for improvement. Guidance on this issue was provided at the IPFR workshop in February 2023. Panels should also cover all the decision-making criteria and document all discussions in sufficient detail. This also includes decisions made by Chairs action.
- Decision rationale provided to the clinician should be clear and concise. Each consideration in the decision-making guide could be addressed to improve clarity and avoid repetition.

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

### Judicial Review

After a Judicial Review<sup>1</sup> of an IPFR decision in December 2021 the judge found that the WHSSC IPFR Panel had not acted legally. In this respect, the judge deemed that the correct comparator group had not been used, the documentation of the decision was inadequate and the relevant guidance had not been interpreted properly. Feedback from the legal team representing WHSSC expressed a number of issues, including: the size of the panel; the volume of requests taken to each panel meeting; the need for strong chairmanship; and clarity about the wording of the policy and the use of reference materials.

In response to the comments raised, WHSSC implemented a number of changes including:

- an increased number of panel meetings from monthly to every two weeks;
- review of the WHSSC IPFR panel terms of reference to help quoracy of meetings and to ensure robustness and appropriate governance support; and
- strengthened documentation, economic evaluation and use of references.

As part of the response to the Judicial Review, Welsh Government instructed WHSSC to undertake a de minimis review of the IPFR policy. This has been done in collaboration with the IPFR QA group and the Policy Implementation Group, alongside the health board panels. With legal support, the changes to the policy have strengthened the wording around the approach to decision-making by the IPFR panels and the process for documentation and included an update to the complaints process. The updated IPFR policy will be published towards the end of 2023.

<sup>1</sup>Wallpott, R (On the Application of) v Welsh Health Specialised Services Committee & England and Wales High Court (Administrative Court) Dec 3, 2021

## IPFR Workshop

**AWTTC hosted the sixth annual IPFR workshop in February 2023 as a face-to-face event again after holding it online during the COVID-19 pandemic. This workshop was open to IPFR panel members, IPFR teams, clinicians in Wales who complete IPFR application forms and those interested in learning more about the IPFR process.**

Topics covered during the day included:

- lessons learnt from a recent Judicial Review;
- factors to consider when assessing the value of interventions;
- how to submit IPFR requests electronically using the IPFR database; and
- collecting outcome data and how this could be improved.

Delegates were given an overview of the various access routes to treatments in Wales. In a pre-recorded video, a consultant oncologist from Velindre Cancer Centre shared their insights into a clinician's experience of IPFR.



**74 attendees with  
representation from  
each IPFR panel**



**Colleagues attended from Health  
Technology Wales, Public Health  
Wales, all Welsh health boards,  
AWTTC and WHSSC**

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.

Holding the event face-to-face gave all delegates an opportunity to network and develop links across health boards. Delegates could also find out more about the work of AWTTC, Health Technology Wales, WHSSC and Yellow Card Centre Wales by visiting their display stands throughout the day. Videos and presentations from the 2023 workshop, and from past IPFR workshops, are available on the [AWTTC website](#).

"There was a good mix of interactive and listening. I enjoyed the different points of view e.g. co-ordinators, referring clinicians and panel members".



"As a very new panel member, working through example cases was particularly helpful."



"The interview with the clinician was excellent."



"The health economics presentation was extremely useful – allowing making pragmatic health economic decisions in real-life IPFR situations. Much appreciated."



## Summary of the data

Overall the data for 2022–2023 show:

**335**

IPFRs were processed across Wales



an increase of 20 compared with 2021-2022

**8**

(5.2%) more requests for medicines in 2022–2023 compared with the previous year



**10**

The number of IPFRs for non-medicines increased by 10 (5.8%) compared with the previous year

**79%**

of all IPFRs were approved



an increase of 4% compared with the previous year

**85%**

of medicine requests were approved



**73%**

of non-medicine requests were approved.

## 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	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
WHSSC	Welsh Health Specialised Services Committee

### 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.