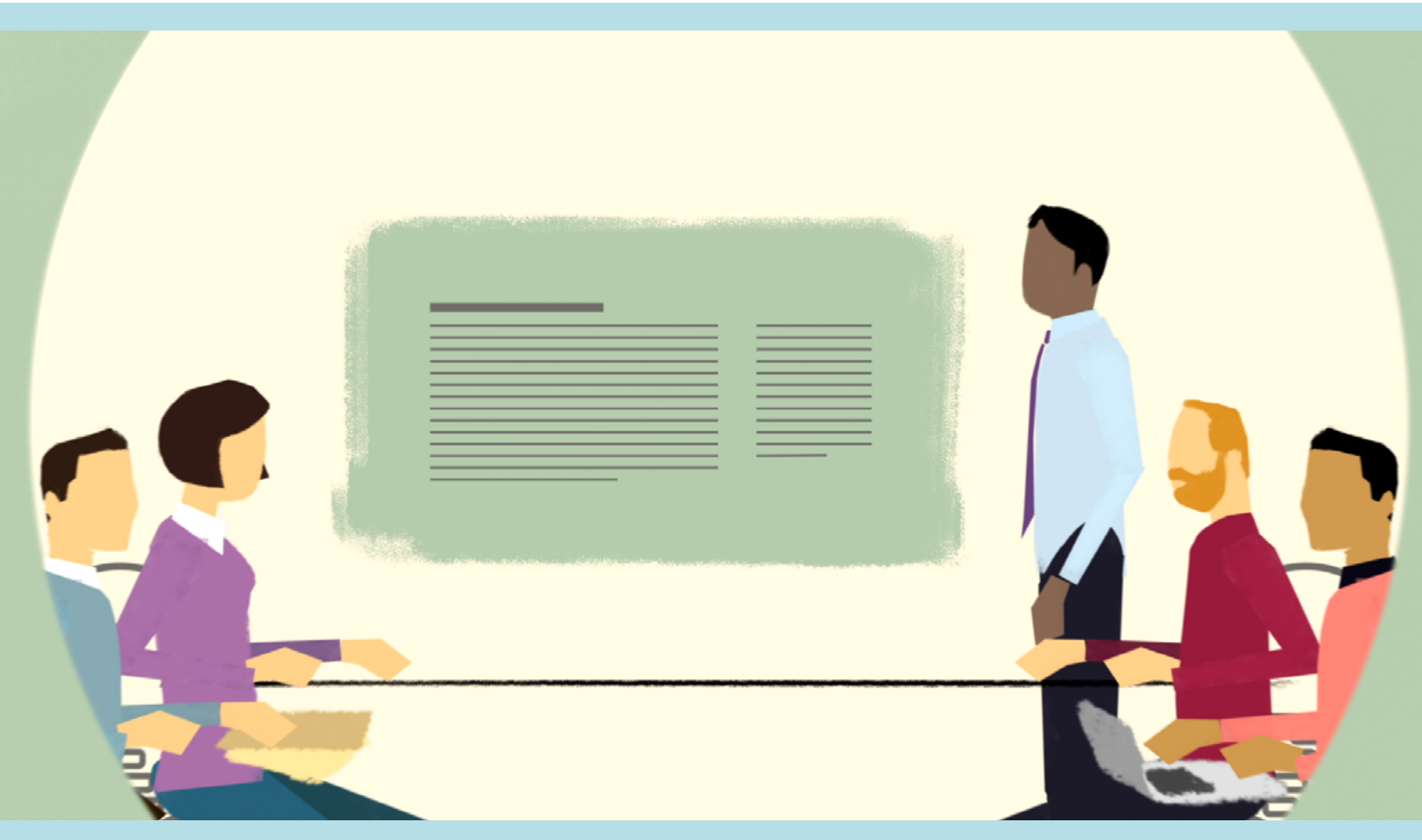
AWTTC
All Wales Therapeutics & Toxicology Centre
Canolfan Therapiwteg a Thocsicoleg Cymru Gyfan

GIG CYMRU NHS WALES

Individual Patient Funding Request (IPFR)

Annual Report 2021-2022



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

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AWTTC Clinical Director's statement

The year 2021–2022 continued to be a challenge for the NHS in Wales. The COVID-19 pandemic adding strain to our service but in itself also challenged how we operated in the NHS and resulted in many changes to practice for the better. The practice of moving to virtual panel meetings continued for many Individual Patient Funding Request (IPFR) panels and it will be interesting to see whether panels continue along the same vein going forward. It is reassuring to see that, despite the external pressures placed on the panel members, the quality of the IPFRs considered and the process behind them continues to improve. The number of lay representatives across the health board panels remains low and this is something that AWTTC are helping to address in 2022 through a campaign to support lay recruitment.

Prof James Coulson
Clinical Director, AWTTC

The small increase in medicine-related requests is likely due to the continued effects of the pandemic. It will be interesting to see if this levels out over the following year. Following a year on year increase in positive recommendations the approval rate remains stable and we hope reflects upholding of the improvement in applications submitted both in terms of relevant requests but also the quality of the applications.

The IPFR workshop was also held virtually in 2021. It was good to see clinicians attending the meeting which included a specific session for them on completing IPFRs online. This provided some useful feedback which has been passed on to the IPFR database developers and we hope to work on as part of the next phase of development of the database. We welcomed two health economists to run sessions on assessing value for money, a beginner and then a more advanced session. There were some interesting discussions on the ethical issues in relation to the mock cases provided and a thought-provoking session on judicial review. Something that we will be picking up again at our next workshop in October 2022.

The One Wales team were busy writing reviews this year and a new medicine was assessed, sorafenib as maintenance treatment post-transplant for acute myeloid leukaemia, which received a positive decision. We had some lovely feedback from the patient organisations who had submitted completed questionnaires welcoming the news and were looking forward to working again with AWTTC in the future.

02

Executive summary

- In 2021–2022 the total number of IPFRs across Wales decreased slightly compared with 2020–2021. This was mainly due to a decrease in non-medicine IPFRs which was driven by a decrease in requests for positron emission tomography (PET) scans (down 53% from 2020–2021) and is likely to be due to a review of Welsh Health Specialised Services Committee (WHSSC)'s PET-Computed Tomography commissioning policy in 2021.
- In 2021–2022 the number of IPFRs for medicines increased again. There were 12 (8.5%) more requests for medicines in 2021–2022 compared with the previous year. This may reflect the need to change treatments due to the COVID-19 pandemic.
- The number of IPFRs approved remained stable, with 75% of all IPFRs approved in 2021–2022. The approval rate for medicine IPFRs increased slightly to 80% in 2021–2022 (compared to 77% in 2020–2021).
- The approval rate for non-medicines was 70% in 2021–2022, similar to that seen in 2020–2021 (73%).
- The number of patient outcomes reported has improved in 2021–2022 from the previous year, from 7% to 15% of all IPFRs considered. 83% of patients were reported to have a complete or partial response to treatment and 80% had an improvement in quality of life.
- The number of cohorts created for medicines requested through IPFR remains low in 2021–2022. The AWTTC team will continue to monitor for cohorts through the database for medicines and non-medicines.
- Despite a dip in the criteria met in January to March 2021, most likely as a result of the winter pandemic surge, the percentage of IPFR quality assurance criteria met had returned to pre-pandemic levels for the latter nine months of 2021.
- The IPFR workshop was held online in 2021 and received very positive feedback. Videos and presentations from the workshop can be viewed on the AWTTC website.
- One medicine was assessed through the One Wales Medicines process and 11 reviews were conducted. All decisions are displayed on the AWTTC website.

03 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 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 AWTTC website (awttc.nhs.wales/ipfr).

AWTTC supports the IPFR service in Wales by:

- 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 members.

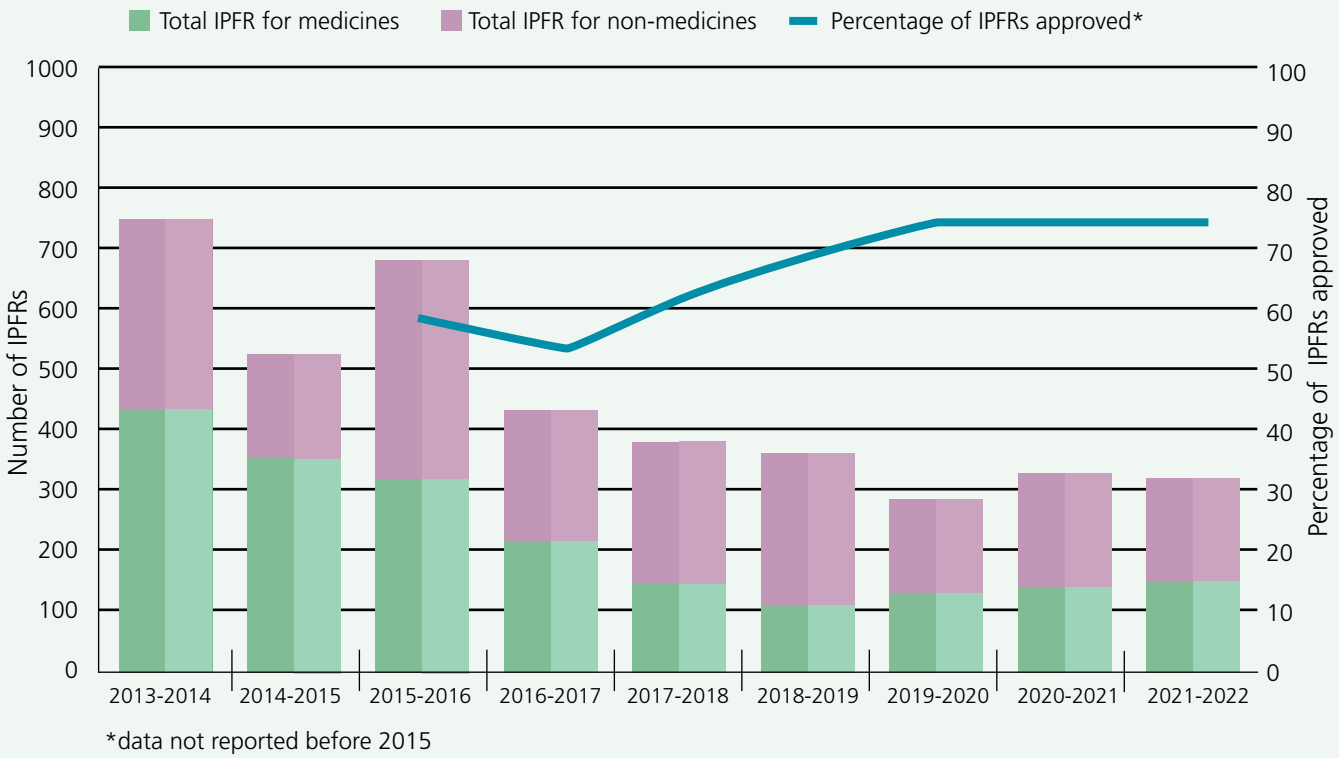
04

Individual Patient Funding Requests

Between 1 April 2021 and 31 March 2022, health boards in Wales and WHSSC considered a total of 315 IPFRs. This is a slight decrease compared with 2020–2021 (Figure 1).

Of the 315 IPFRs, 153 were for medicines and 171 were for non-medicines; 9 requests were for medicines and non-medicines. In 2021–2022, the numbers of requests for medicines increased and numbers of requests for non-medicines decreased, compared with 2020–2021.

Figure 1: Total number of IPFRs considered in Wales from 2013–2014 to 2021–2022

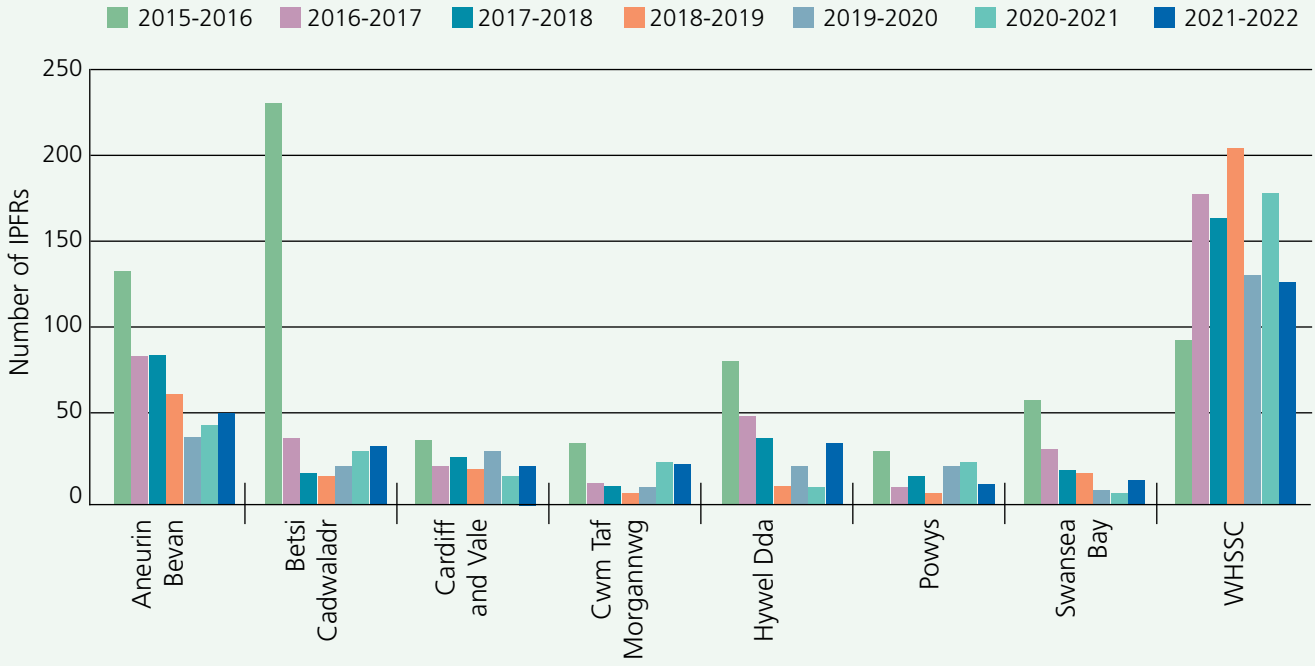


The approval rate of all IPFRs during 2021–2022 was 75%, little change from 74% during 2019–2020 and 2020–2021. The approval rate data were not reported for the years before 2015; AWTTC produced the first annual IPFR report for 2015–2016.

The decrease in total IPFRs was not seen across all health boards in Wales. Figure 2 shows the numbers of IPFRs considered by each health board panel in Wales over the past seven years. Five panels showed an overall increase in IPFRs in 2021–2022, and three panels (including WHSSC) showed decreases. The total number of IPFRs across the health boards (excluding WHSSC) stayed at a median of 23 in 2021–2022, the same as in 2020–2021.

The rate of IPFRs per 100,000 population for each health board during 2021–2022 ranges from 4 to 10 (see Figure 3). Powys Teaching Health Board still had the highest rate of IPFRs per 100,000 population in 2021–2022, although the rate has decreased from last year (decrease of 7 IPFRs per 100,000). Hywel Dda University Health Board showed the largest increase (increase of 4 IPFRs per 100,000) followed by Swansea Bay University Health Board (increase of 2 IPFRs per 100,000). However, the numbers are low for both of these panels and so small numerical differences translate to larger difference in rates.

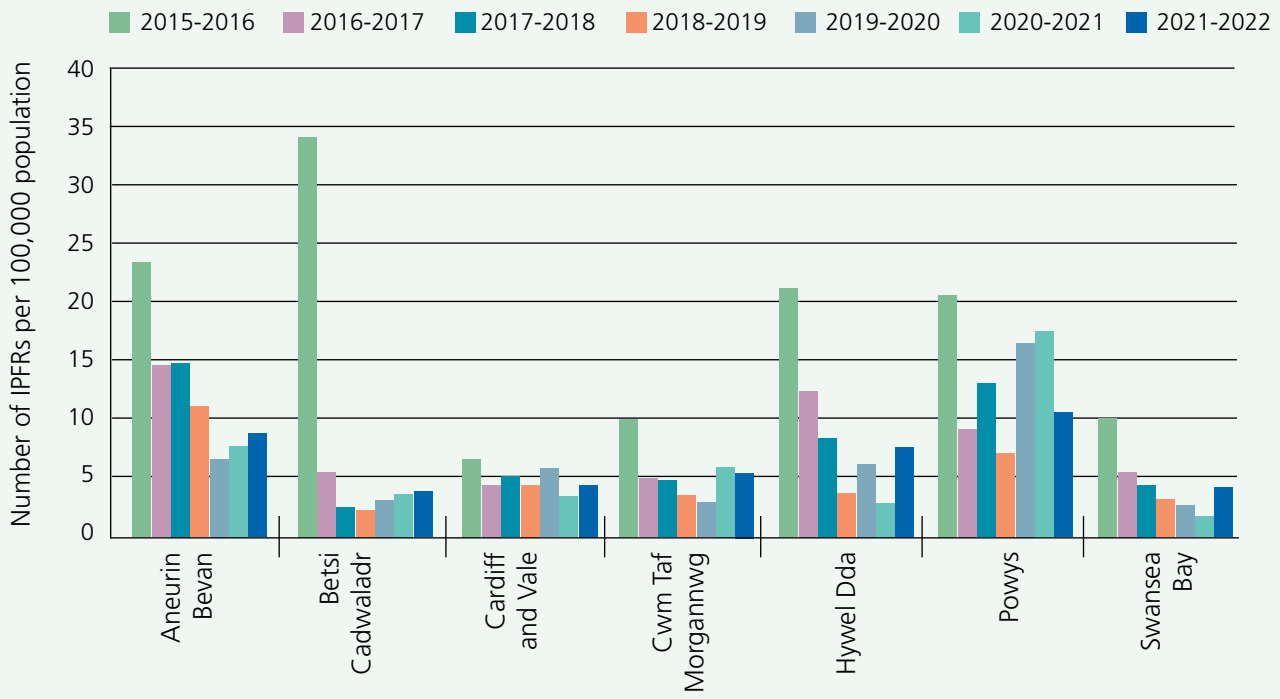
Figure 2: Number of IPFRs within each health board in Wales, including WHSSC, from 2015–2016 to 2021–2022



Continued funding

Continued funding requests are for treatments that had previously been approved and require an extension to treatment. The number of requests in 2021–2022 did not differ significantly from 2020–2021, with 58 requests for continuation of funding: 51 for medicines and 7 for non-medicines. Most requests (86%) were approved.

Figure 3: Rate of IPFRs per 100,000 population for each health board in Wales from 2015–2016 to 2021–2022



Independent reviews

If an IPFR is declined by the panel an independent review of the IPFR process may be requested either by the clinician or by the patient with the support of the clinician. A review may be requested only if the clinician or patient believe that process has not been followed in accordance with the policy. The review request must fall into one of three strictly limited grounds as defined by the policy:

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

In 2021–2022, two requests for reviews were submitted. One was referred for review on grounds one and two, but the original decision was upheld. One case was referred on all three grounds and, considering the findings of a judicial review, was referred back for reconsideration by the panel and the request was subsequently approved.

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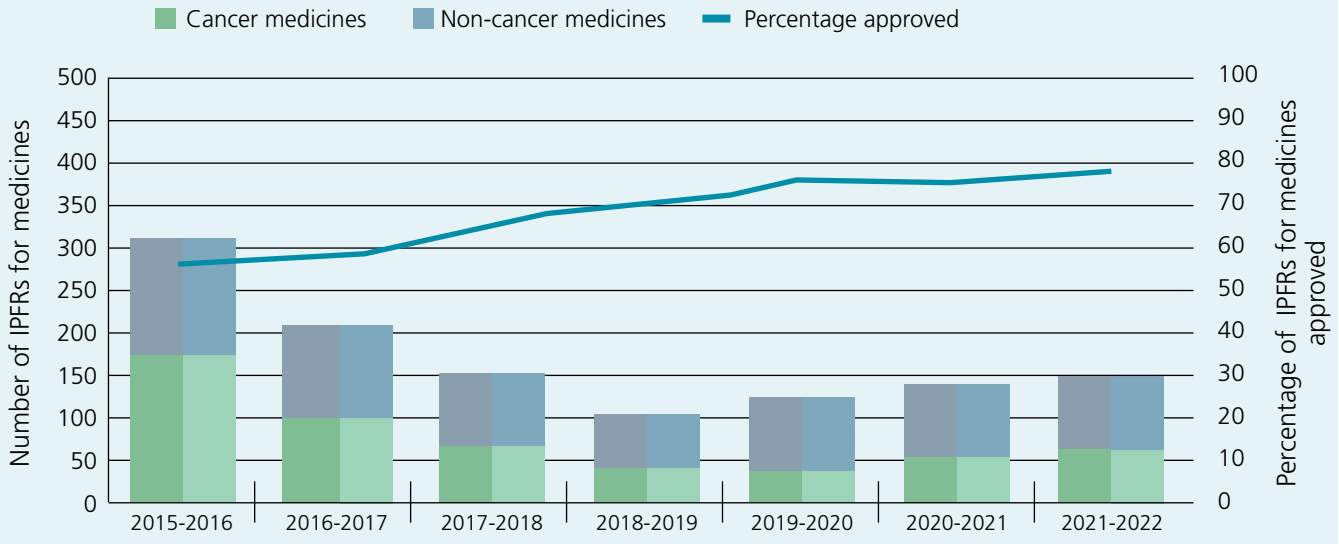
IPFRs for medicines by health board and Welsh Health Specialised Services Committee (WHSSC)

During 2021–2022 the number of IPFRs for medicines increased to 153, compared with 141 during 2020–2021 (Figure 4). This is the third year running in which IPFRs for medicines have increased.

A total of 122 IPFRs for medicines were approved; 28 were not approved and three IPFRs for medicines were deferred. The approval rate of IPFRs for medicines was 80%, an increase from 77% in 2020–2021.

Figure 4: Number of IPFRs for medicines considered in Wales from 2015–2016 to 2021–2022 and the percentage approved



Requests for an IPFR in relation to a medicine occur for three main reasons:

- Advice in relation to a licensed indication 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 or is unable to recommend the technology.
- The medicine is being used 'off-label', i.e. medicine is used outside the terms of its marketing authorisation (product licence).

During 2021–2022, the number of IPFRs for medicines to treat cancer increased to 63, from 54 in 2020–2021 (Figure 4). IPFRs for other medicines (non-cancer) increased slightly to 90, compared with 87 during 2020–2021.

05

Figure 5: Number of IPFRs for medicines within each health board in Wales, including WHSSC, from 2015–2016 to 2021–2022

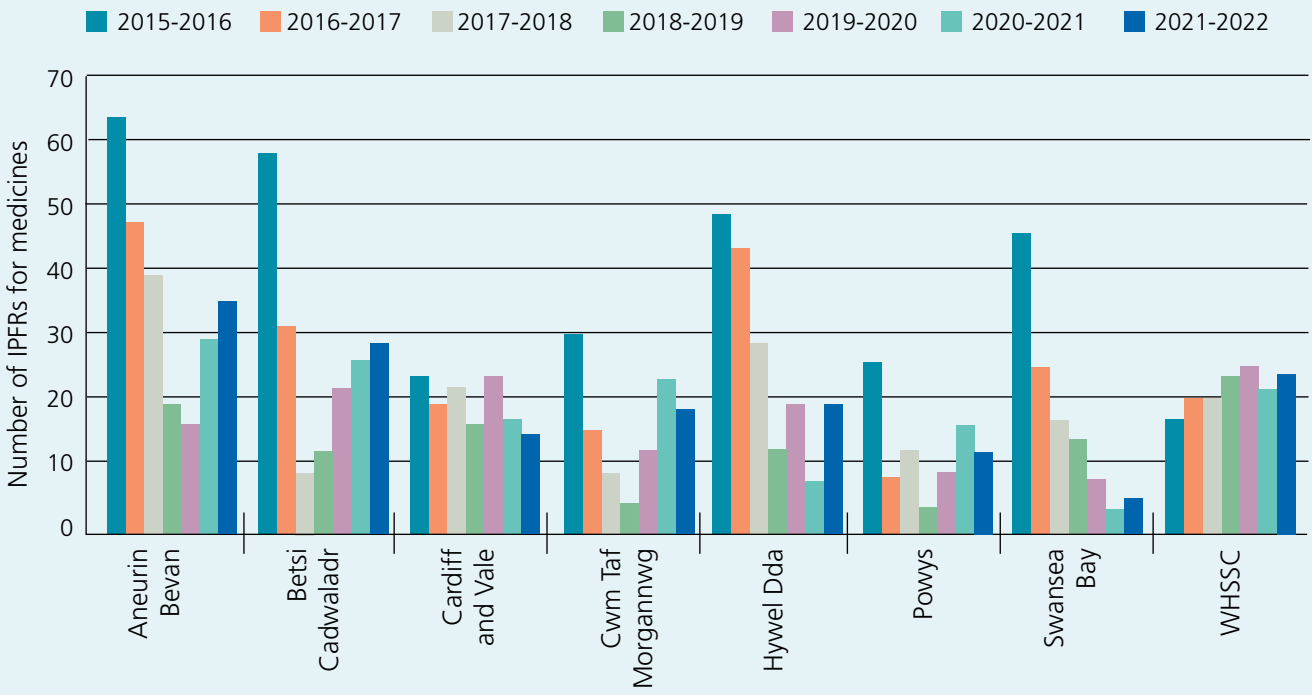


Figure 5 shows the numbers of IPFRs for medicines by health board and WHSSC over the past seven years. Over half of the 153 IPFRs for medicines were received by two health boards and WHSSC: Aneurin Bevan University Health Board had 34 requests, Betsi Cadwaladr University Health Board had 28, and WHSSC had 23.

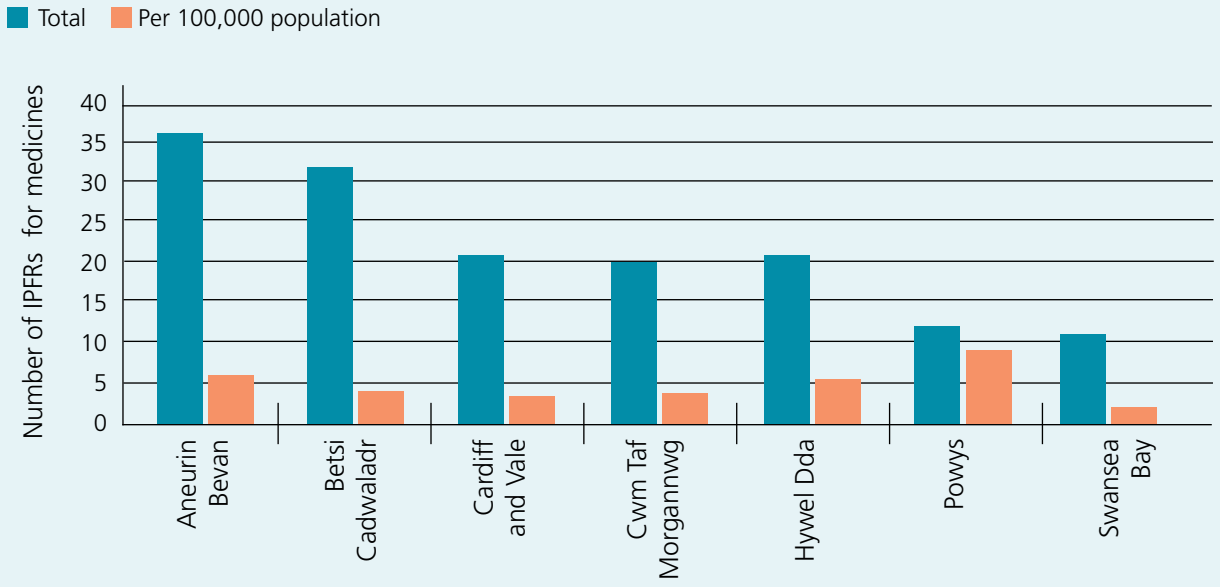
The numbers of IPFRs for medicines vary across the health boards. During 2021-2022, four health boards showed an increase in IPFRs for medicines: following a decrease to 7 in 2020–2021, Hywel Dda University Health Board had a large increase to 19 in 2021–2022. Three health boards showed slight decreases in IPFRs for medicines.

Figure 6 shows the rate of IPFRs for medicines per 100,000 population for each health board in Wales in 2021–2022. IPFRs for medicines received by WHSSC have been added to the appropriate local panel medicine IPFRs for each health board. The numbers of IPFRs for medicines per head of population ranged from 3 per 100,000 in Swansea Bay University Health Board, to 9 per 100,000 in Powys Teaching Health Board (Figure 6).

05

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 requests for medicines has increased annually to 19 in 2021–2022. Despite an increase in the past three years, the mean number of requests in 2015–2016 remains statistically significantly higher ($p < 0.05$) than those in each of the subsequent years.

Figure 6: Number of IPFRs for medicines and per 100,000 population within each health board in Wales in 2021–2022

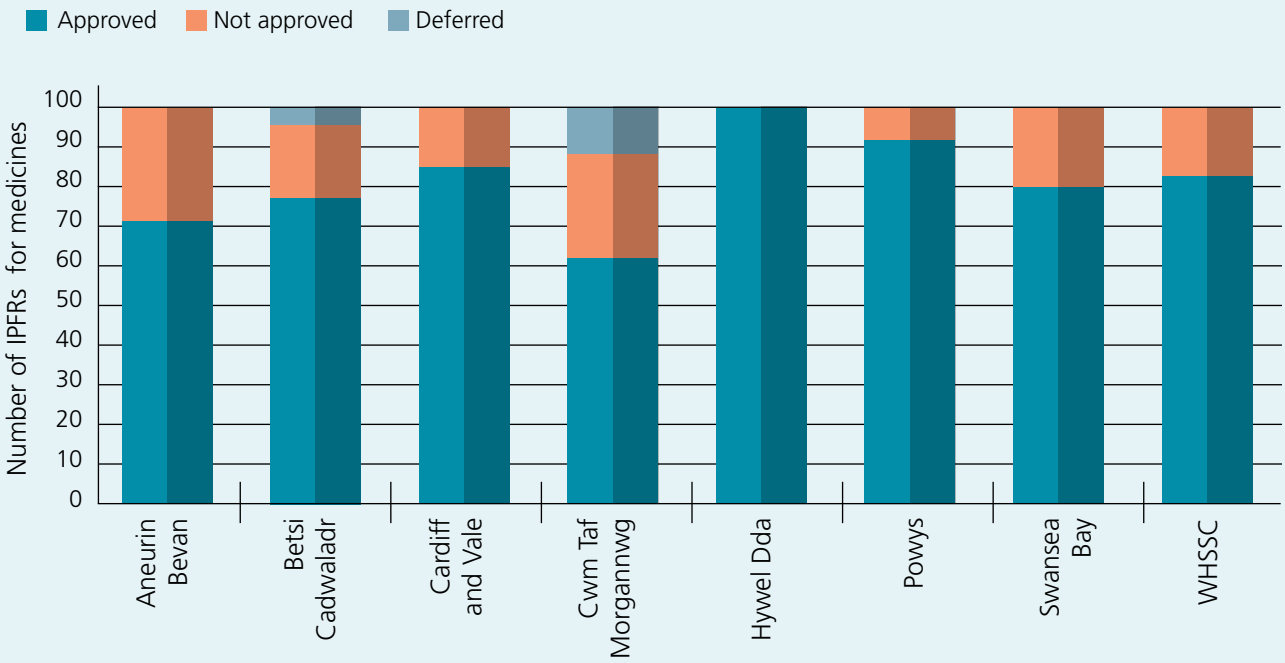


The fall in requests from the high in 2015–2016 is thought to be due to a better awareness of the most appropriate routes for accessing medicines in Wales. Also, following positive One Wales Medicines advice, IPFR applications are no longer submitted for those indications. It is likely that the increase in requests for medicines is linked to the pandemic; in particular to avoid hospital attendance for routine drug administration, especially for immuno-suppressed patients, although these increases are not statistically significant.

During 2021–2022 the percentage of IPFRs for medicines approved by each health board and WHSSC ranged from 61% to 100% (Figure 7). Hywel Dda University Health Board was the only health board to approve 100% of IPFRs for medicines in 2021–2022. Five health boards approved 80% or more of IPFRs for medicines.

Approval rates for IPFRs varied between health boards. It may be that changes 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 may markedly affect the percentage approval rate.

Figure 7: Percentage of IPFRs for medicines approved, not approved and deferred within each health board in Wales and WHSSC in 2021–2022

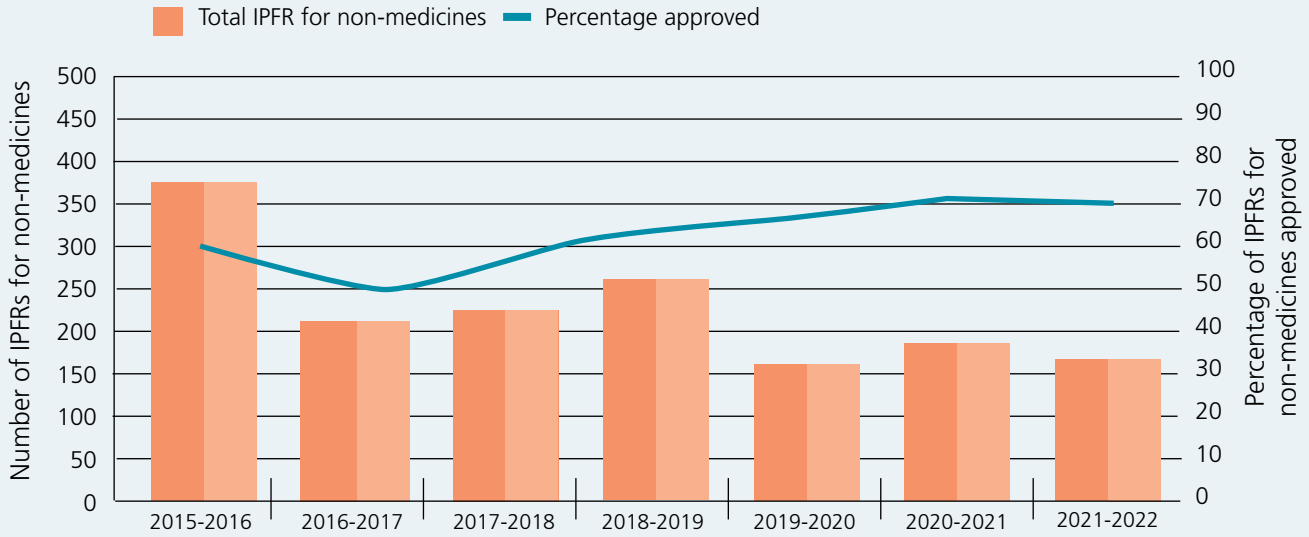


06

IPFRs for non-medicines by health board and WHSSC

During 2021–2022, the numbers of IPFRs for non-medicines decreased slightly to 171, compared with 190 during 2020–2021 (Figure 8). The rate of approvals of non-medicine IPFRs during 2021–2022 was 70%, similar to that of 2020–2021. During 2021–2022, a total of 120 IPFRs for non-medicines were approved, 46 were not approved and five were deferred.

Figure 8: Numbers of IPFRs for non-medicines and percentage approved between 2015–2016 and 2021–2022



During 2021–2022, as in previous years, WHSSC considered most of the non medicine IPFRs (n = 115; Figure 9). However, 115 IPFRs is a decrease of 24% compared with 2020–2021, and was probably driven by a decrease in IPFRs for positron emission tomography (PET) scans (73 in 2020–2021 compared with 34 in 2021–2022).

Aneurin Bevan University Health Board had the next highest number of non medicine IPFRs (n = 16; no change from 2020–2021), followed by Hywel Dda University Health Board (n = 12) and Swansea Bay University Health Board (n = 12). The numbers of non-medicine IPFRs were low in the other health boards.

Four health boards showed an increase in non-medicine IPFRs, which might reflect efforts to reduce the backlog of NHS work caused by the COVID-19 pandemic. Betsi Cadwaladr University Health Board was the only health board that had no non medicine IPFRs during 2021–2022.

The annual median number of IPFRs for non-medicines across health boards (not including WHSSC) has fluctuated over the past seven years between 3 in 2019–2020 and 9 in 2015–2016. The median number of IPFRs was 8 in 2021–2022.

Figure 9: Number of IPFRs for non-medicines within each health board in Wales, including WHSSC, from 2015–2016 to 2021–2022

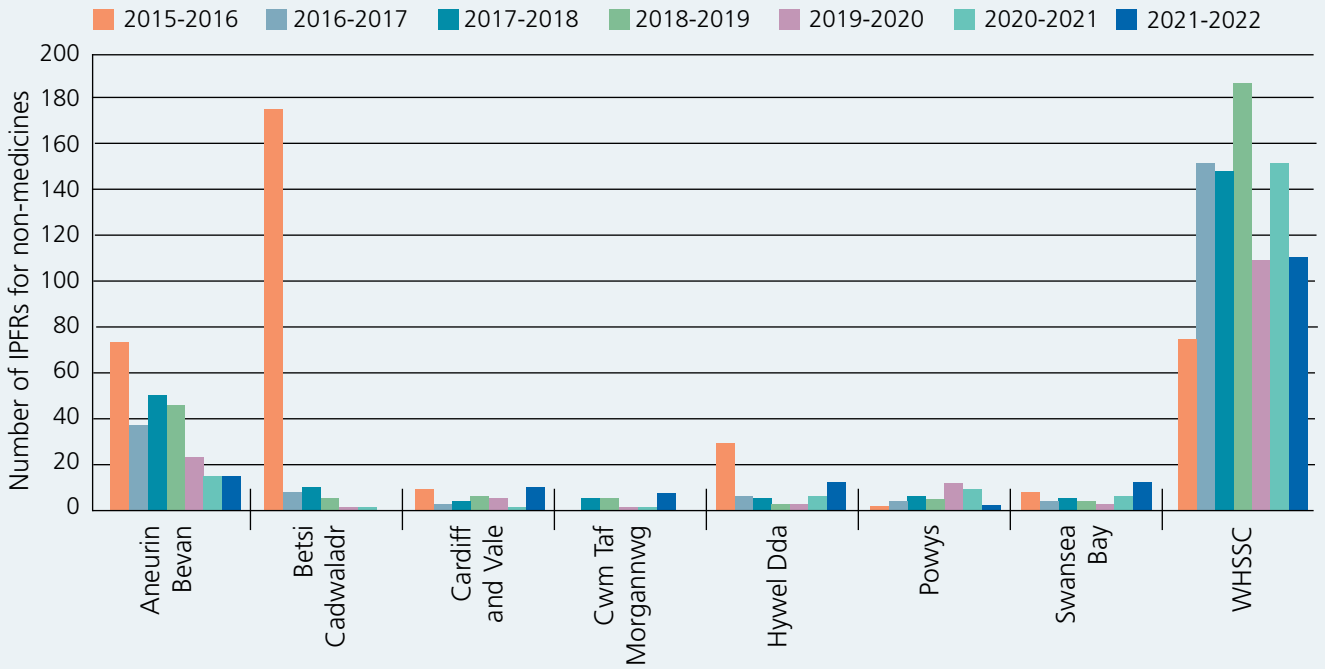
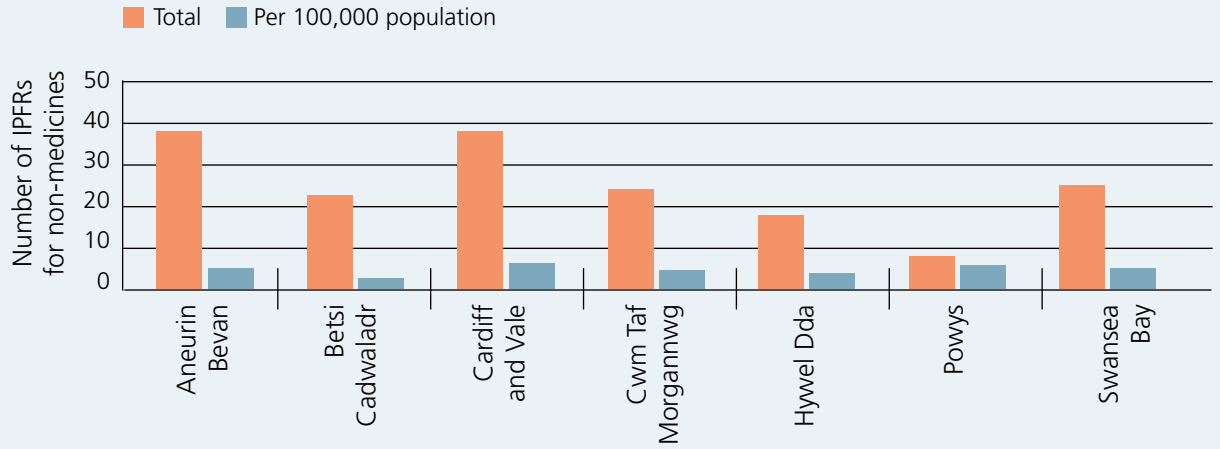


Figure 10 shows the number of non-medicine IPFRs and rate per 100,000 population for each health board in Wales. All WHSSC's non-medicine IPFRs have been added to the appropriate local panel non-medicine IPFRs for each health board. The rate of non-medicine IPFRs per 100,000 population is similar across most health boards, and ranges from 3 in Betsi Cadwaladr University Health Board to 7.5 in Cardiff & Vale University Health Board.

The types of non-medicine interventions requested through IPFR are shown in Figure 11. The numbers of PET scan requests more than halved – decreasing from 73 in 2020–2021 to 34 in 2021–2022. This reflects updates to the WHSSC PET commissioning policy (CP50a) published in May 2021. The revised policy includes additional indications and expanded criteria to support the funding of PETs where previously these requests were managed by the IPFR process. New indications include: primary colorectal cancer; gall bladder cancer; gastrointestinal stromal tumours (GIST); lymphoma and prostate cancer as well as paraneoplastic indications and some dementia indications.

Figure 10: Number of IPFRs for non-medicines and per 100,000 population within each health board in Wales in 2021–2022



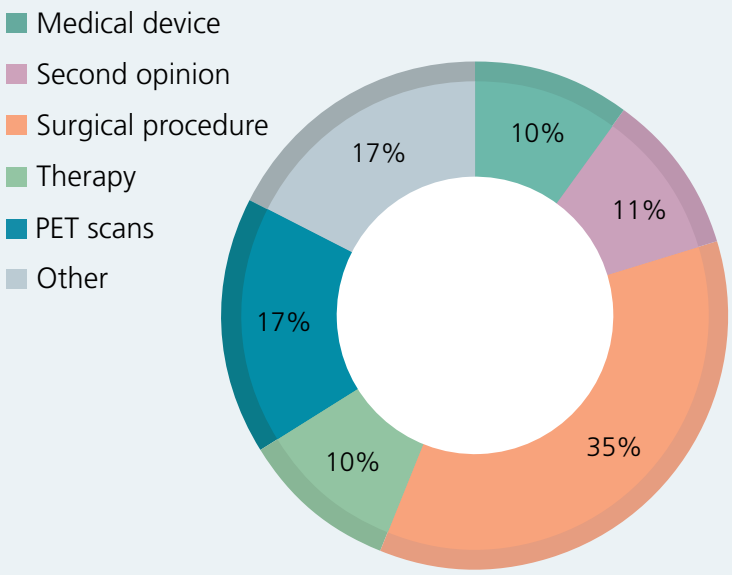
As in the previous year, the second most frequent non-medicine IPFR was for *in vitro* fertilisation (IVF) (n = 11; 6% of non-medicine IPFRs), this is likely due to delays in referrals as a result of COVID-19 and patients falling outside of policy criteria. The next most frequent request was for cytoreductive surgery and hyperthermic intraperitoneal chemotherapy (HIPEC) (n = 8; 5%). There were no requests for microprocessor-controlled prosthetic knees during 2021–2022 which had accounted for 5% of non-medicine requests in 2020–2021; WHSSC published a new Microprocessor Controlled Prosthetic Knees policy in December 2021.

During 2021–2022 there was a marked increase in IPFRs for second opinions, to 22 in total. 2020–2021 saw a fall in IPFR for second opinions (n = 7). In 2021–2022 there was also an increase in IPFRs for surgical procedures (n = 73), up from 51 in 2020–2021. This could likely show a return to more usual NHS work after the COVID 19 pandemic.

During 2021–2022, a total of 66 of all non-medicine IPFRs were for cancer treatment or diagnosis. Most of them were requests for PET scans, though there were fewer requests for PET scans for cancer in 2021–2022 (n = 25) than in 2020–2021 (n = 64) following addition of new indications for cancer to the updated policy. Surgical procedures were the second most-requested non-medicine IPFRs for cancer treatment or diagnosis; these were for cytoreductive surgery and HIPEC (n = 8; 14%) followed by stereotactic ablative body radiosurgery (n = 5; 9%). Of the 21 non medicine IPFRs for therapy, 11 were for cancer treatment or diagnosis; similar numbers of requests were received in 2020–2021.

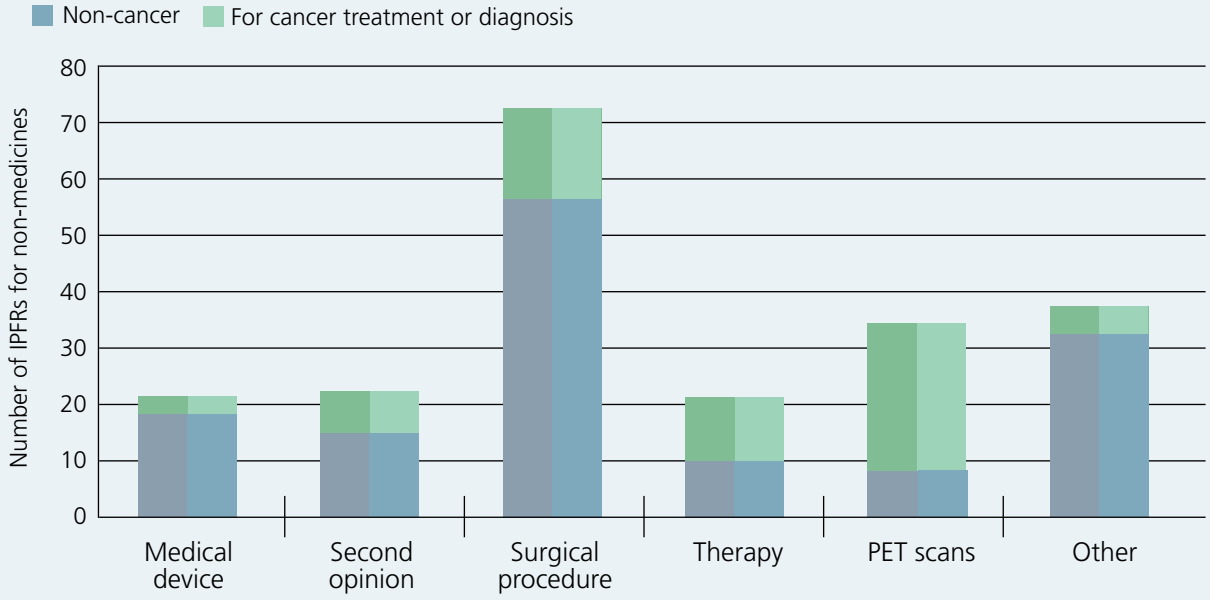
Most of the other IPFRs (not for cancer treatment or diagnosis) during 2021–2022 were requests for surgical procedures (n = 57). Only three of 21 IPFRs for medical devices were for cancer treatment or diagnosis, and 7 of the 22 IPFRs for a second opinion were for cancer treatment or diagnosis. Of the 36 requests for 'other' treatments, only 4 were for cancer treatment or diagnosis. Figure 12 shows the number of IPFRs by intervention type for cancer and non-cancer treatment or diagnosis.

Figure 11: Percentage of non-medicine IPFRs by type in 2021–2022



In 2019–2020 a process was piloted and IPFR teams can now request non-medicine evidence summaries from Health Technology Wales (HTW). In 2021–2022 HTW provided evidence summaries for 14 topic areas to support IPFR panel decision making in 17 cases.

Figure 12: Number of IPFRs for non-medicines by intervention type in 2021–2022



07

IPFR and the One Wales Medicines process

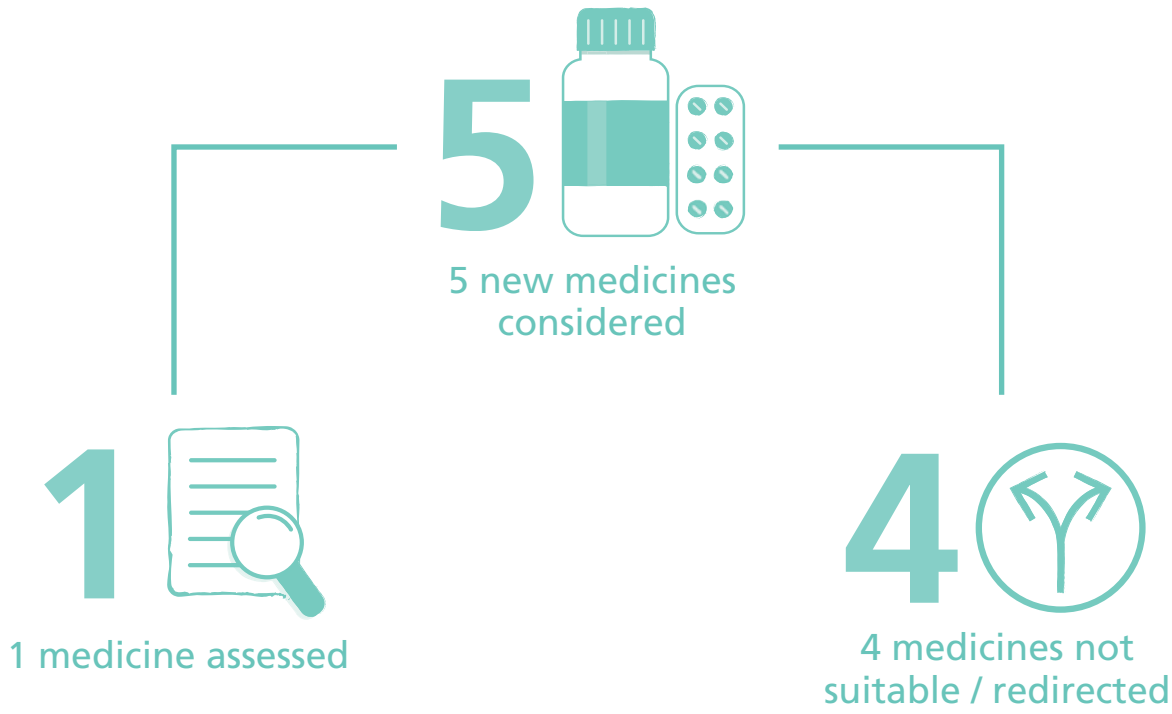
Analysis of IPFR submission data from health boards across Wales has been used to inform other aspects of the AWTTC work programme, and in particular the One Wales Medicines Process which has been assessing medicines since May 2016. The process has been developed to facilitate one single agreed decision for NHS Wales on access to particular medicines for a group of patients (a patient 'cohort'). Medicines and patient cohorts are identified for the One Wales Medicines Process by signals from activity in the IPFR panels, from WHSSC, the Chief Pharmacist Peer Group or clinician groups. More information on the One Wales Medicines Process and current One Wales decisions are available on the AWTTC website (awttc.nhs.wales/one-wales).

Despite another slight increase in IPFRs for medicines in 2021-2022, emerging cohorts of IPFRs have continued to decrease since the inception of the One Wales Medicines Process. This is attributed to the implementation of the New Treatment Fund in 2017, earlier guidance from NICE around the time of licence and the Cancer Drugs Fund now applying in Wales. In addition, the NICE COVID-19 rapid guideline (NG161) and list of interim treatments published by NHS England were adopted for use in Wales allowing access to some alternative treatments.

Ongoing monitoring of the IPFR data has shown that soon after publication of a positive One Wales Medicines Advisory Group decision, applications are no longer submitted for these indications. This positively demonstrates that the process effectively reduces the burden on IPFR panels and encourages equity of access to these medicines across Wales. The new One Wales assessment of sorafenib for maintenance treatment of acute myeloid leukaemia was requested by clinicians in Wales to avoid the need to submit repeated IPFRs. It is estimated that approximately four patients annually would be eligible for this treatment. Of the nine One Wales decisions reviewed in 2021-2022, seven had been identified through IPFR patient cohorts.

11 medicines are available through the One Wales programme

One Wales Medicines Process activity in 2021–2022



08

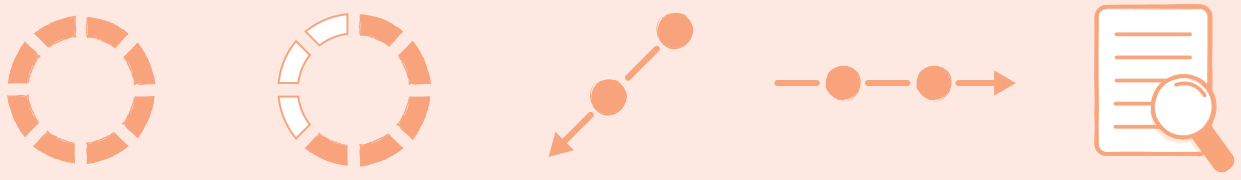
Patient outcomes

Of data collected during 2021–2022, patient outcome data were available for 49 patients, all following requests where the intervention had been approved. This represents outcome data for 15% of all IPFRs for the year, an increase on the 7% of outcomes reported in 2020–2021.

Thirty four of the outcomes were reported with applications for continued funding of medicines which had been previously approved.

The figures below 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. The majority of outcomes (94%) were reported for funded medicines. Most patients received the funded treatment, treatment was delayed in one case, in another case treatment was not started as the patient had deteriorated and died.

Response to treatment



8	31	2	2	4
Complete response	Partial response	Disease Progressed	Stable disease	Not assessable

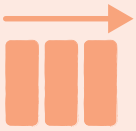
Of the feedback provided 39 of 47 patients (83%) were reported to have a complete or partial response to treatment and 20 of 25 patients (80%) had an improvement in quality of life. Treatment was discontinued in ten cases: in three cases the treatment course had ended; three patients had disease progression; three patients died (two following disease progression), and one patient suffered treatment-related toxicity.

At time of follow up four patients could not be assessed: one being a request for a diagnostic procedure; one patient had deteriorated and died before receiving treatment; one patient had

deteriorated and treatment commenced but died before an effect could be determined. A fourth patient had died due to complications not related to the medication. A further two patients died; one had demonstrated a partial response to treatment and an improvement in quality of life, the other had deteriorated and died despite treatment.

Quality of life following treatment

20 Improved 

1 Maintained 

4 Reduced 

Although the number of outcomes reported has improved in 2021–2022 from the previous year, the number remains lower than AWTTC would like. The collection of outcome data is important to monitor and analyse whether or not a treatment has been effective. The majority of outcomes are submitted with a request for continued funding for treatment. Consequently, the majority of outcome data relates to patients who are benefitting from an approved medicine. Data on one off treatments are lacking, in particular for non-medicines such as surgical procedures or medical devices. There is also a lack of outcomes reported where treatment requests were declined. It is important for the IPFR service to monitor outcomes to provide information on the impact of decisions in relation to patients. AWTTC will continue to work with IPFR panels and clinicians to explore ways to improve the collection of outcomes.

48 patients received treatment

36 continue to receive treatment

Reasons for stopping treatment

3 Death

3 Disease progression

3 End of treatment course

1 Treatment related toxicity

The majority of IPFRs approved in 2021–2022 for which we have outcome information were associated with evidence of clinical benefit and a maintenance or improvement in quality of life. The number of cases for which outcome data are available was an improvement from the previous year but remains low overall.

09

Quality Assurance Advisory Group

In 2021 IPFR panels across health boards in Wales continued to provide a timely and efficient service. With a minimum reduction in the percentage of assessment criteria met during the second surge of the pandemic in January to March the group noted a return to the expected high standards of service for the rest of the year.

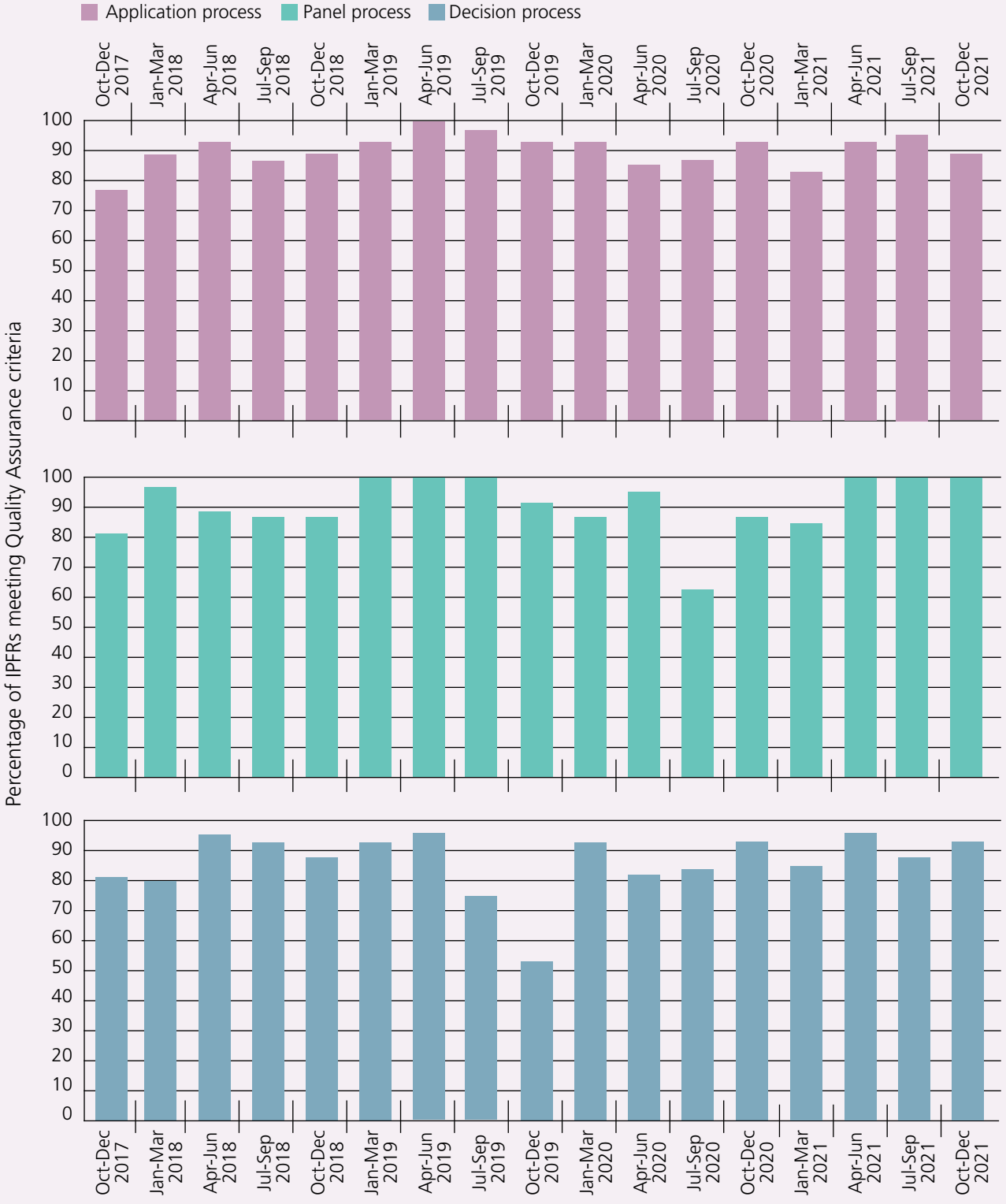
The IPFR Quality Assurance Advisory Group was established in January 2018 to examine and address variation between panels in relation to consistency in the decision-making process. The group reduced meeting frequency to every six months during 2020 due to disruption caused by the pandemic. In 2021 the continuation of six-monthly meetings was considered; the group consensus was to resume quarterly meetings to allow for timely identification and response to any quality assurance issues. The group therefore met four times in 2021-2022 to assess IPFRs covering the 2021 calendar year.

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 AWTTC. 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 Group are available on the AWTTC website (awttc.nhs.wales/ipfr).

Figure 13 shows the percentage of criteria met for each quarter from October 2017 to December 2021. Following a recovery in the percentage of criteria met in the second half of 2020, in the first quarter of 2021 there was a slight drop in the criteria met in all three areas. This coincides with the second pandemic surge which will have impacted IPFR panel members, staff as well as clinician time for preparing IPFR applications. From April to December 2021 the percentage of criteria met recovered to 90% and above for all aspects with the exception of the decision process in July to September where the percentage meeting criteria fell to just below 90%.

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, Welsh Government.

Figure 13: Percentage of IPFRs assessed meeting the Quality Assurance process criteria between October 2017 and December 2021



Action points raised thorough these assessments have resulted in a general improvement in IPFRs meeting the criteria from 2018 to 2022. In 2020 the exceptional circumstances of the pandemic resulted in a dip in improvements due to short term local adaptions which meant some processes fell outside of the assessment criteria. In 2021 panels have adapted work practices and developed new ways of working, the percentage of quality criteria met have reached pre-pandemic levels from April to December with 100% of panel process criteria met during these latter nine months. The group noted that following an increase in Chair's action decisions for non-urgent cases in 2020, in 2021 Chair's action was reserved for urgent cases only and full IPFR panels were once again convened on a regular basis. There was also an improvement in the proportion of cases that were considered by panels within the requested timeframe, with 93% of cases meeting the urgency deadline in 2021 compared with 70% in 2020.

Action points from 2020

In the previous year the group advised that the bilingual patient letter should be used by all panels, this is now routine practice across Wales.

Following the initial disruption due to the pandemic, panel were expected to convene every two weeks to ensure timely decisions for all applications submitted with an urgency of 'soon' (within three weeks) or non-urgent (within four to six weeks). Most panels are managing to meet regularly and the requested urgency has been met in the majority of cases.

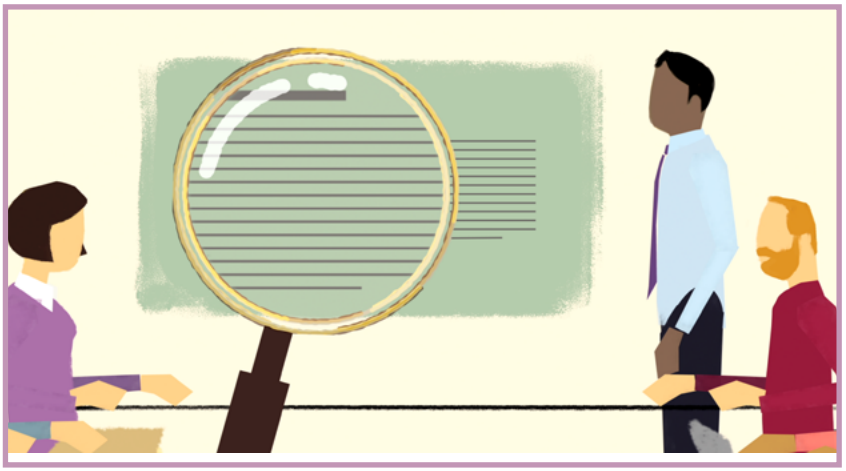
In 2020 the group had noted an increase in the use of Chair's action for decisions that were not considered urgent. In 2021 Chair's action decisions have been reserved for urgent cases by the majority of panels.

Action points from 2021

- IPFR teams should ensure that documentation is sufficient for a case to be considered by panel. Additional information may be requested as required or may be available on the IPFR database repository.
- Costs for interventions should be corroborated before panels meet; the cost of alternative treatments should be provided to allow for fully informed value for money considerations.
- It is considered good practice to send a letter to the patient when a decision has been deferred to keep the patient informed of a possible delay.

- Evidence summaries to support non-medicine IPFRs can be requested from Health Technology Wales (HTW). The group encourage panels to use this service to ensure panels have sufficient information for consideration of non-medicine requests.
- Many panels do not have lay member presence, AWTTC are implementing a recruitment drive for lay members over the coming year.

The Quality Assurance Advisory Group considers that overall the IPFR process was being followed in line with the IPFR policy. Despite a dip in the criteria met in January to March, most likely as a result of the winter pandemic surge, the percentage of quality criteria met had returned to pre-pandemic levels for the latter nine months of 2020. The Quality Assurance Advisory Group are have returned to quarterly meetings in 2021 to ensure timely feedback and monitoring of recommendations.



Over 80% of IPFRs reviewed in 2021 met the process criteria

In 2021 93% of cases met the urgency deadline

10

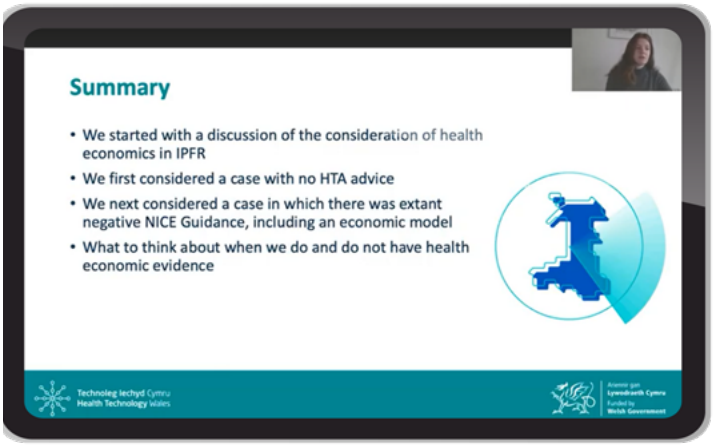
IPFR Workshop

The fifth IPFR workshop was held in November 2021 as an online event due to the COVID-19 pandemic. The half-day virtual workshop was open to IPFR panel members, IPFR teams, clinicians who complete applications and those with an interest in learning more about the IPFR process.

After welcoming delegates to the workshop, separate sessions for panel members, clinicians and IPFR teams were held simultaneously in virtual break-out rooms. The content of each session was specifically tailored to the needs and training requirements of these different IPFR roles with time for questions and discussion.

Topics included:

- For panel members - health economics and applying concepts to IPFR using worked examples
- For clinicians – how to make a good IPFR submission and what to cover in discussions with the patient
- For IPFR teams – using the IPFR database and processing e-submissions



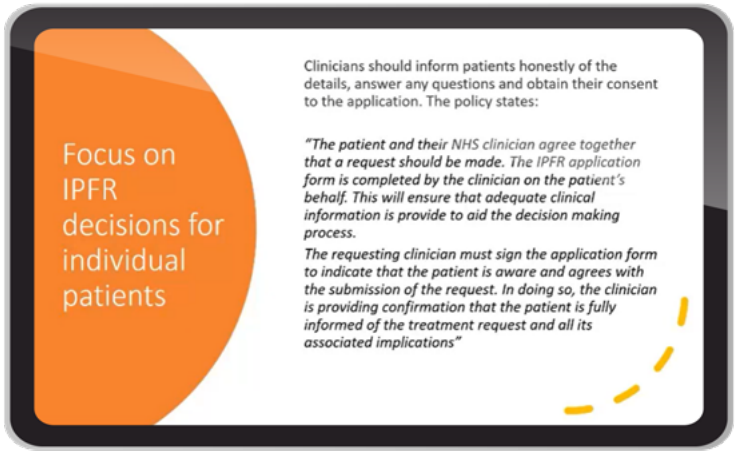
As in previous years, clinic sessions were also held, where delegates could choose to hear about two out of the following three topics: ethics, legal and attending WHSSC as a panel member.

"I think it worked well. There was good discussion about the different points different virtual panels discussed."

58 attendees, with representation from each IPFR panel

10

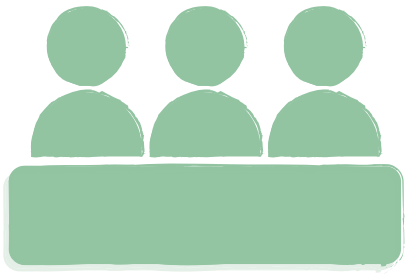
Delegates were then brought back together and had opportunity to ask questions to the clinic session expert panel before discussing in more detail two IPFR cases that had been sent out to each IPFR panel in advance of the workshop.



"Very good and informative."

Despite the challenges of holding the workshop online, feedback was very positive. Videos and presentations from the event were made available from the AWTTC website. It is planned that the next workshop will revert to being a face-to-face event.

"There was a good mix of presentations as well as questions and interaction with participants. I attended the IPFR Panel Teams session which was really helpful."



Colleagues from Health Technology Wales, Public Health Wales, Welsh health boards, Velindre Cancer Centre and the Welsh Health Specialised Services Committee were in attendance.

11 Summary of the data

Overall the data for 2021–2022 show:

315
IPFRs were processed across Wales

12
or 8.5% more IPFRs were requested for medicines in 2021-2022 compared with the previous year

19
or 10% fewer IPFRs were requested for non-medicines compared with the previous year

75%
of all IPFRs were approved

70%
of non-medicine requests were approved.

80%
of medicine requests were approved

12

Glossary and additional note

AWMSG	All Wales Medicines Strategy Group
AWTTC	All Wales Therapeutics and Toxicology Centre
E-submissions	Electronic submissions
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 (formerly Interim Pathways Commissioning 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.