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

GIG CYMRU NHS WALES

Individual Patient Funding Request (IPFR)

Annual Report 2019/2020

PAMS
Patient Access to Medicines Service
Mynediad Claf at Wasanaeth Meddyginiaethau

Contents

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AWTTC Clinical Director's statement

2019/2020 – A big change for AWTTC, as our Clinical Director, Professor Phillip Routledge, retired after 38 years of working in NHS Wales and Dr Sharon Hopkins stepped down from her role as Chair of the One Wales Interim Pathways Commissioning Group (IPCG) and as public health representative on the Individual Patient Funding Request (IPFR) Quality Assurance Group.

In 2019 I became Interim Clinical Director for AWTTC and Chair of the IPFR Quality Assurance Group. There have been many changes to AWTTC in a short space of time and I am thankful for the support of AWTTC staff during this time.

The IPFR Quality Assurance Group has met quarterly since January 2018 and I am very grateful for the contribution from Dr Sharon Hopkins over that time. We are delighted to have welcomed Dr Stuart Bourne as our new Public Health representative taking up his role in the latter half of 2019. Since the establishment of the Group it is rewarding to see continued improvement in the criteria used to assess the IPFR process in NHS Wales. Going forward we will continue to monitor how we assess the quality of the IPFR process and encourage our group members to attend local panels to view meetings first hand.

Since the inception of the One Wales IPCG, Dr Sharon Hopkins wisely and skilfully chaired the Group. In 2019 Dr Hopkins became Interim Chief Executive for Cwm Taf University Health Board and stepped down from the Group. Although Dr Hopkins will be sadly missed we wish her every success in this new role. The new Chair of the One Wales IPCG is Professor John Watkins, Honorary Consultant in Public Health Medicine, who is taking on the challenge with gusto despite the recent changes to our work during COVID-19.

Dr James Coulson
Interim Clinical Director, AWTTC

"The IPFR Quality Assurance Group and IPFR panels work closely to ensure fair and consistent access to health care resources for the people of Wales"

And finally, to continue on the theme of change, we have made some changes to the layout of the annual report this year. We hope you like the new style and find the report informative and interesting to read.

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Executive summary

- There has been a continuing annual decline in the number of Individual Patient Funding Requests (IPFRs) across Wales since 2015/2016. In 2019/2020, there were approximately 19% fewer IPFRs overall and 37% fewer non-medicine IPFRs compared with the previous year. The decline in non-medicine IPFRs was driven by a reduction in requests for positron emission tomography (PET) scans as a result of an update to Welsh Health Specialised Services Committee's (WHSSC's) PET-Computed Tomography commissioning policy in June 2019 which included several new indications. In 2019/2020 there were 31% more requests for medicines compared with the previous year; this is the first increase in requests for medicines since 2013/2014.
- More IPFRs were approved in 2019/2020 (74%) compared with the previous year (68%). The number of IPFRs approved has continued to increase year on year for medicines and non-medicines. The continued increase in approval rate may be due in part to more complete IPFR applications and fewer inappropriate IPFR submissions. IPFR panels also have greater clarity on rationale for approving decisions following the move in 2017 away from the previous concept of 'exceptionality' to 'significant clinical benefit'.
- There were fewer medicines requested for the same indication. This is a continuing trend and is likely to be related to multiple factors including the continued monitoring of requests through the One Wales process; the availability of the New Treatment Fund in Wales which promotes rapid availability of medicines following publication of Health Technology Assessment (HTA) advice, access to new medicines on the Cancer Drugs Fund and earlier guidance from the National Institute for Health and Care Excellence (NICE) around the time of licence.
- Similar to the previous year, outcome data were provided for 13% of IPFRs. These data included outcomes on treatment response and quality of life. Encouragement is still needed to improve reporting of outcome data to IPFR panels.
- The Quality Assurance Advisory Group continue to be impressed with the documentation and adherence to processes by IPFR panels in Wales. The Group were pleased to see improvement in areas highlighted in the previous year. In 2019, more than 90% of IPFRs reviewed met the assessment criteria for applications and panel meetings. A lack of evidence for non-medicine IPFRs was highlighted during a review of the Quality Assurance process in May 2019. Through collaboration with Health Technology Wales, IPFR teams can now request non-medicine evidence summaries.
- In 2019/2020, five new medicines were considered for the One Wales Interim Commissioning process, three of which were assessed and the remaining two were not considered suitable for assessment by this process. Six One Wales Interim Commissioning decisions were reviewed in 2019/2020; the availability in NHS Wales continued for four medicines, the fifth medicine was reassessed and the original decision to not support its use was overturned. The sixth medicine was retired from the One Wales process in 2019/2020 because it became standard of care.

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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, requests are received for healthcare that fall outside the range of services agreed. Individual Patient Funding Requests (IPFR) are 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. This can include, for example, a request for a surgical device or piece of equipment, medicine or surgical intervention. The process followed and documentation used are uniform across all health boards and WHSSC and adhere to the NHS Wales IPFR policy. All IPFRs are logged on the All Wales IPFR database which is administered by the NHS Wales Informatics Service (NWIS) in collaboration with the All Wales Therapeutics and Toxicology Centre (AWTTC). Further information about the IPFR service in Wales can be found on the AWTTC website (www.awttc.org/ipfr).

AWTTC has supported the IPFR service in Wales since 2015 through implementation of several initiatives:

- AWTTC works with NWIS to develop and maintain a national database for logging all IPFR applications. The system is used to provide reporting data, monitor cohorts of medicines (a medicine being used for the same indication but requested for multiple patients across Wales) for One Wales. It can also be used by clinicians in Wales to submit IPFR applications electronically.
- The IPFR Quality Assurance Advisory Group was formed in 2018 and meets quarterly to assess IPFRs from each panel in relation to the IPFR policy. Examples of good practice and recommendations are shared across the health boards and WHSSC to promote consistency of service in NHS Wales.
- AWTTC hosts an annual IPFR workshop for IPFR panel members and applicant clinicians. The workshop provides training for panel members and applicant clinicians, and the opportunity for attendees to network with panel members from other health boards.

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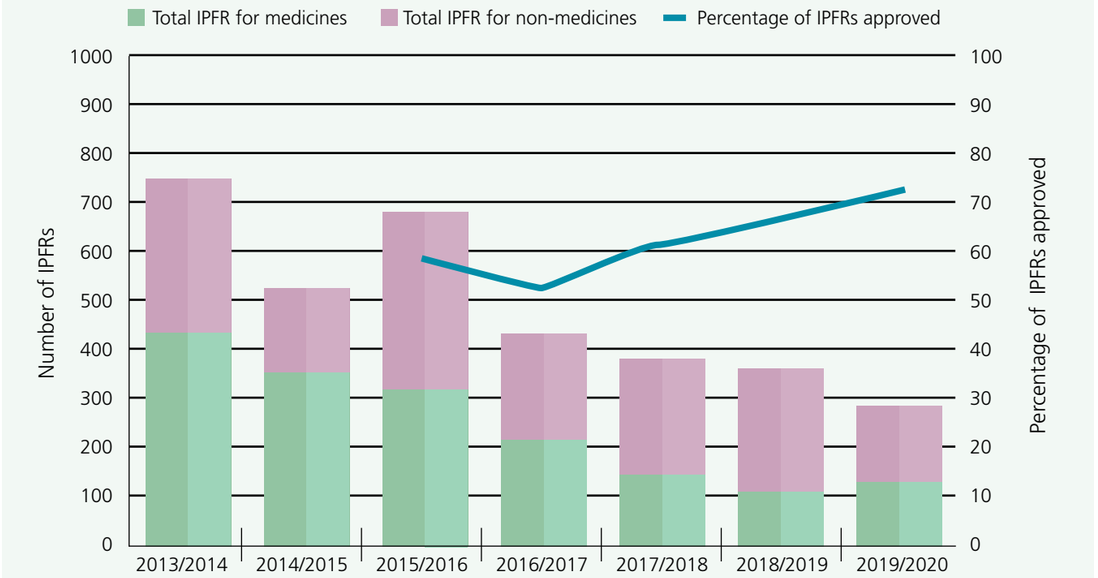
Total IPFRs considered in Wales during 2019/2020

A total of 288 IPFRs were considered between 1 April 2019 and 31 March 2020: 129 for medicines, 158 for non-medicines and 3 for medicines and non-medicines within the same application. This shows a continued decrease in the total number of IPFRs since 2015/2016 (Figure 1).

Figure 1: Total number of IPFRs considered in Wales from 2013/2014 to 2019/2020



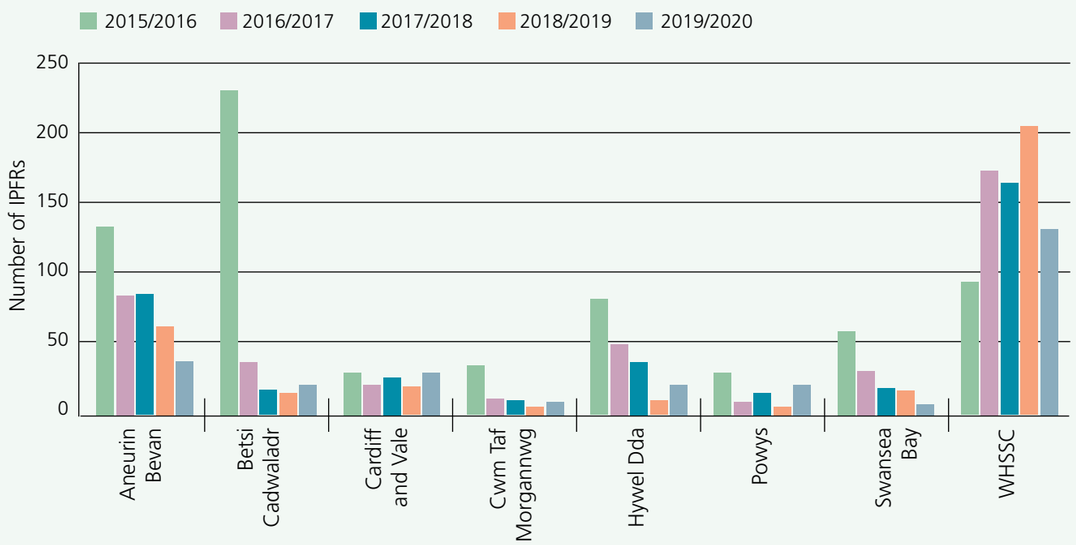
The number of requests for medicines has increased in 2019/2020 for the first time in seven years with an increase of 31% compared with the previous year. This may be due to individual changes in health board practices and will continue to be monitored. Requests for non-medicines have decreased in 2019/2020 by 37% compared with the previous year. The approval rate for IPFRs has continued to increase year on year with 74% of all IPFRs approved in 2019/2020 (Figure 1). Approval rate data from 2013/2014 and 2014/2015 are not available because this information was not previously collated before AWTTC started producing the annual IPFR report.

The numbers of IPFRs considered by each panel[1] for the last five years are shown in Figure 2. Three panels have shown an overall decrease in IPFRs in 2019/2020, whilst five panels have shown

[1] In April 2019 a boundary change came into effect creating Swansea Bay University Health Board and Cwm Taf Morgannwg University Health Board from the former Abertawe Bro Morgannwg and Cwm Taf University Health Boards, respectively. The IPFR panels remain unchanged within the new health boards. This report uses the new health board names and revised population figures have been used for this year's figures.

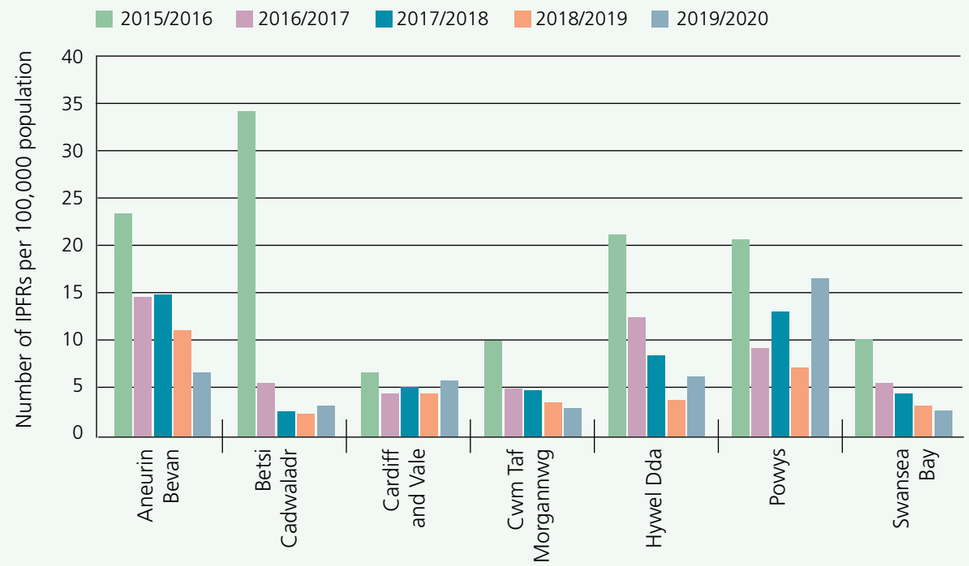
modest increases. The total number of IPFRs across the health boards (excluding WHSSC) reduced from a median of 53 in 2015/2016 to a median of 22 in 2019/2020. There was a statistically significant decrease in the median number of requests to health boards in 2018/2019 and 2019/2020 when compared to 2015/2016 ($p < 0.001$ and $p < 0.05$, respectively). These differences were maintained when adjusting for the health board populations.

Figure 2: Number of IPFRs within each health board in Wales, including WHSSC, from 2015/2016 to 2019/2020



In 2019/2020, the number of IPFR applications per 100,000 population for each health board panel range from 3 to 17, as shown in Figure 3. The majority of health boards show little change since 2018/2019. There has been an ongoing decrease in the rate of IPFRs considered by Aneurin Bevan University Health Board which continues in 2019/2020 with a decrease of 4 per 100,000 since last year. Hywel Dda University Health Board and Powys Teaching Health Board show increases of 3 and 10 IPFRs per 100,000 population respectively in 2019/2020 since last year, although it is difficult to draw any conclusions from these figures due to the low numbers. The increase in the number of requests received in Powys Teaching Health Board are split equally between medicine and non-medicine requests. Part of the increase in medicine requests came from providers outside Wales and this may be due to current commissioning processes.

Figure 3: Number of IPFRs per 100,000 population for each health board in Wales from 2015/2016 to 2019/2020



Moreover, the increase in non-medicine requests relates to a number of Interventions Not Normally Undertaken. Powys Teaching Health Board has the highest rate of IPFRs per 100,000 population in 2019/20 due to the relative increase in the number of requests received and its population size compared with other health boards.

Continued funding

Continued funding requests are for treatments that had previously been approved and require an extension to treatment. In 2019/2020 there were 25 continued funding requests for medicines and 3 requests for non-medicines.

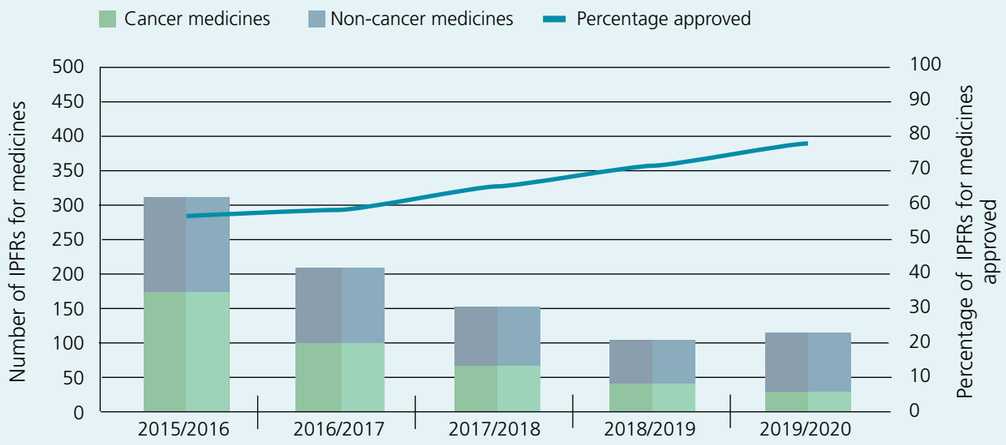
Independent reviews

For IPFRs that are reviewed and then not recommended by the panel, and where the patient and their clinician feel that the process has not been followed in accordance with the IPFR policy, an independent review of the IPFR process may be requested. In 2019/2020 one request for a review was submitted on the grounds that the panel gave unreasonable weight to particular factors. The independent panel did not uphold the grounds of the review and the original decision stood.

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

The number of IPFRs for medicines increased in 2019/2020 (n = 131) compared with the previous year (n = 101; Figure 4). This is the first increase in medicine IPFRs since first collection and interrogation of IPFR data in 2013/2014. From 2013/2014 to 2018/2019, the number of IPFRs decreased annually. The approval rate for medicine IPFRs has continued to increase year on year since 2015/2016 (Figure 4) and in 2019/2020 a total of 103 (78%) medicine IPFRs were approved and 29 (22%) were not approved.

Figure 4: Total number of IPFRs for medicines considered in Wales from 2015/2016 to 2019/2020 and the percentage approved

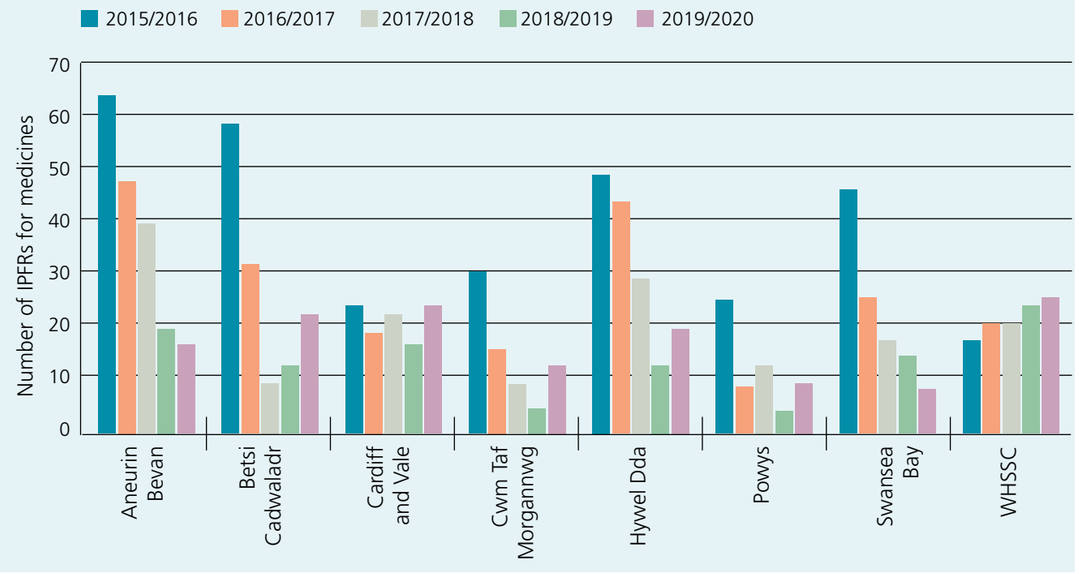


Requests for an IPFR in relation to a medicine occur for three main reasons:

- 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 the medicine.
- The medicine is being used 'off-label', i.e. medicine used outside the terms of its marketing authorisation (product licence).

The number of IPFRs for medicines for the treatment of cancer has continued to decrease annually from 2015/2016 (Figure 4). In 2019/2020, 29% of IPFRs for medicines were for the treatment of cancer compared with 44% in the previous year. Since January 2017, medicines added to the Cancer Drugs Fund list are funded in Wales through the New Treatment Fund, which may explain the reduction in IPFRs for medicines for the treatment of cancer.

Figure 5: Number of IPFRs for medicines within each health board in Wales, including WHSSC, from 2015/2016 to 2019/2020



As in the previous year, WHSSC considered the most IPFRs for medicines (n = 24; Figure 5); a quarter of these were for cancer medicines. The majority of panels considered more IPFRs for medicines in 2019/2020 compared with the previous year, with the exception of Aneurin Bevan and Swansea Bay University Health Board panels who considered less (Figure 5). Figure 6 shows the number of IPFRs for medicines per 100,000 population for each health board in Wales in 2019/2020. The WHSSC medicine IPFRs for each health board have been added to the local panel medicine IPFRs. The number of IPFRs for medicines per head of population ranged from 2 per 100,000 in Swansea Bay University Health Board to 7 per 100,000 in Cardiff and Vale University Health Board and Powys Teaching Health Board (Figure 6). The mean annual number of IPFRs for medicines across health boards reduced from 41 in 2015/2016 to 15 in 2019/2020. The mean number of requests in 2015/2016 was statistically significantly higher ($p < 0.05$) than those in each of the subsequent years.

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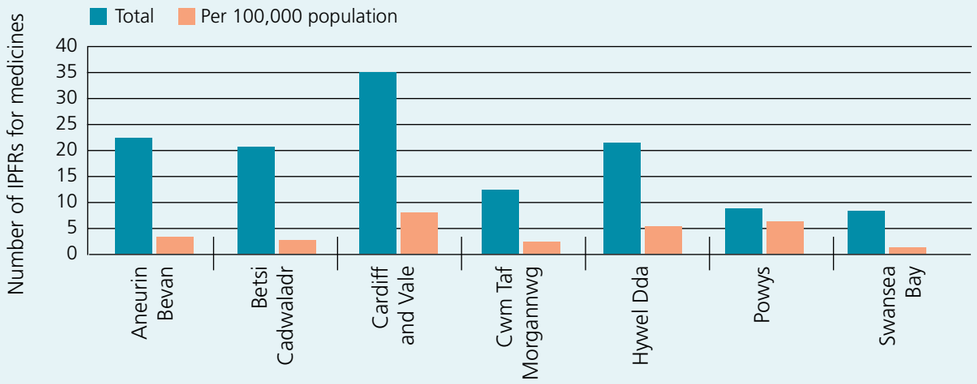
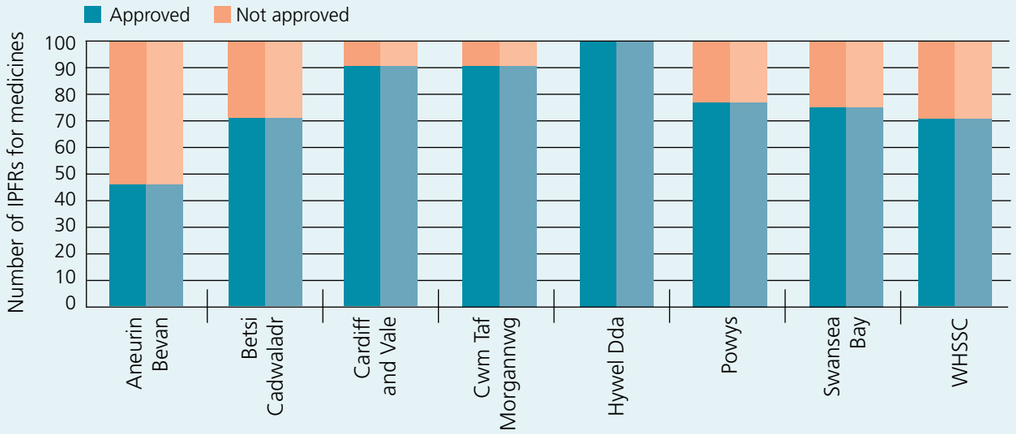
Figure 6: Total number of IPFRs for medicines and per 100,000 population within each health board in Wales in 2019/2020



The percentage of IPFRs approved by each health board and WHSSC in 2019/2020 ranged from 47% to 100% (Figure 7). Cardiff and Vale, Hywel Dda and Swansea Bay University Health Boards had an increase in the percentage of IPFRs approved in 2019/2020 compared with the previous year. The percentage of IPFRs approved in Betsi Cadwaladr University Health Board remained consistent in 2019/2020 as seen in the previous year. The remaining health boards had a small decline in the percentage of IPFRs approved for medicines in 2019/2020 compared with the previous year. Although the approval rates varied between health boards, the overall number of IPFRs were small. Therefore a small change in the approval rate may markedly affect percentage approval rates. Overall the approval rates by panel for 2019/2020 were comparable to 2018/2019 data for each panel.

Figure 7: Percentage of IPFRs approved and not approved within each health board in Wales and WHSSC in 2019/2020



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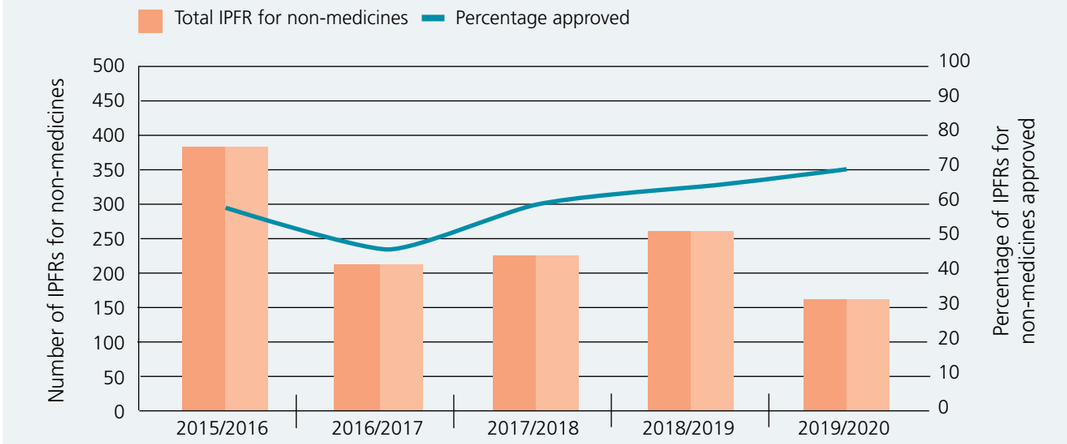
IPFRs for non-medicines by health board and WHSSC

The number of IPFRs for non-medicines has decreased markedly in 2019/2020 (n = 160) compared with the previous year (n = 258; Figure 8), this is the first drop in non-medicine IPFRs since 2016/2017. The approval rate for non-medicine IPFRs has continued to increase year on year since 2016/2017 (Figure 8) and in 2019/2020 a total of 115 non-medicine IPFRs were approved, 41 not approved and 4 deferred.

Figure 8: Total number of IPFRs for non-medicines and percentage approved between 2015/2016 and 2019/2020



As in many of the previous years, the highest number of non-medicine IPFRs were considered by WHSSC (n = 112; Figure 9); this is a 39% decrease since last year driven by a reduction in requests for positron emission tomography (PET) scans. The next highest number considered in 2019/2020 was by Aneurin Bevan University Health Board where the number of non-medicine IPFRs has decreased by 51% since last year. There is no single identifiable reason for this decrease but it may be that a number of interventions requested last year are now included in service level or long-term agreements. It is also possible that with the introduction of new technologies such as robotic surgery over the past two years, fewer requests for complex open surgery are required. Powys Teaching Health Board was the only panel who considered more non-medicine IPFRs in 2019/2020 with an increase from 5 in 2018/2019 to 13 in 2019/2020 (Figure 9). The annual median number of IPFRs across health boards for non-medicines reduced from 9 in 2015/2016 to 3 in 2019/2020, although this reduction was not statistically significant.

Figure 9: Number of IPFRs for non-medicines within each health board in Wales, including WHSSC, from 2015/2016 to 2019/2020

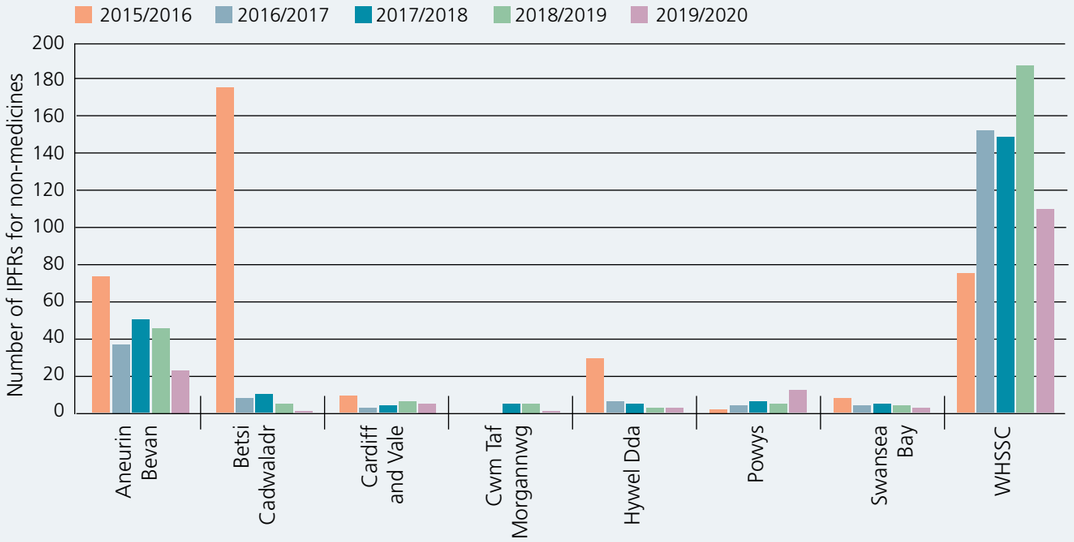
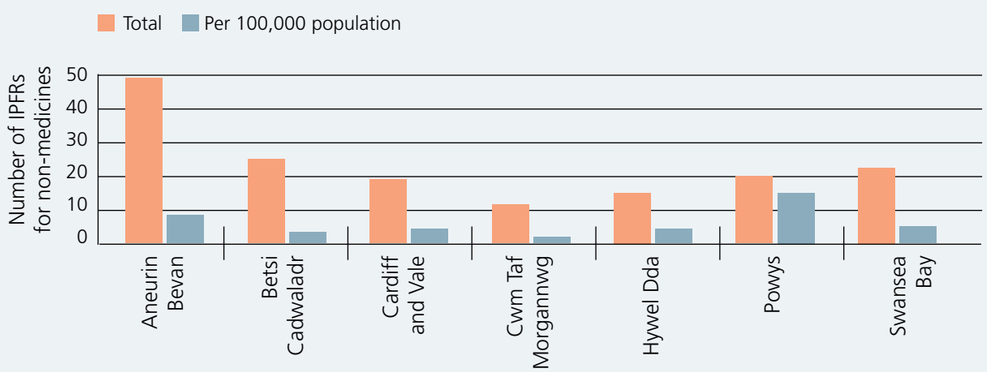


Figure 10 shows the number of non-medicine IPFRs per 100,000 population for each health board in Wales. The WHSSC non-medicine IPFRs for each health board have been added to the local panel non-medicine IPFRs. Figure 10 shows that the number of non-medicine IPFRs per 100,000 population is similar for the majority of health boards, ranging from 3 to 8. Powys Teaching Health Board is the exception with 15 non-medicine IPFRs per 100,000 population; this represents a total of 20 non-medicine IPFRs of which 7 were considered by the WHSSC panel.

Figure 10: Total number of IPFRs for non-medicines and per 100,000 population within each health board in Wales in 2019/2020



The types of non-medicine interventions requested are shown in Figure 11. The number of PET scan requests has decreased in 2019/2020 from 85 the previous year to 54. In June 2019, WHSSC published and updated their PET-Computed Tomography commissioning policy which included several new indications. It was anticipated that this would reduce the number of IPFRs for PET scans; a further reduction may be expected in 2020/2021 when the new policy will have applied for the full year.

Figure 11: Percentage of IPFRs for types of non-medicine within each health board in Wales, including WHSSC, between 1 April 2019 and 31 March 2020

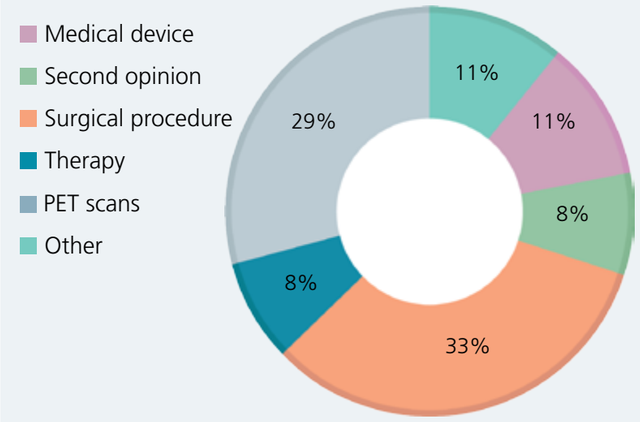
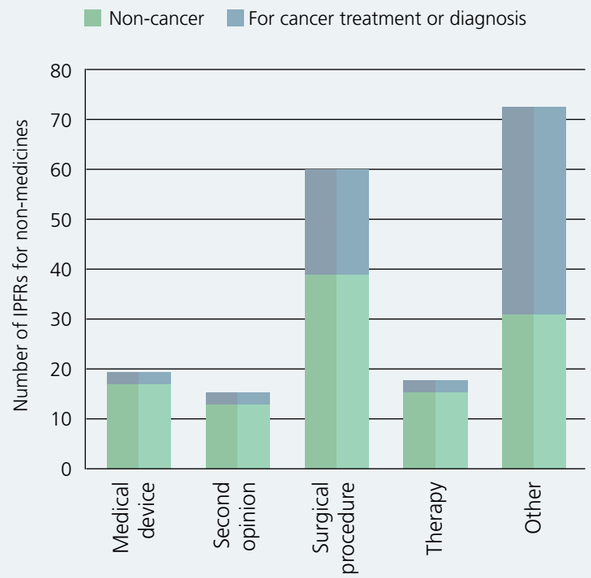


Figure 12: Number of IPFRs for non-medicines by intervention type from 1 April 2019 to 31 March 2020



In 2019/2020 a total of 67 IPFRs were for non-medicine interventions for the treatment or diagnosis of cancer. The majority of these were for PET scans (n = 38; 57%). The second most frequent non-medicine IPFR for cancer was for cytoreductive surgery with hyperthermic intraperitoneal chemotherapy (HIPEC) (n = 14; 21%). The remaining 22% of non-medicine IPFRs for cancer indications were for a variety of procedures, assessments and therapies. Figure 12 shows the number of IPFRs for cancer and non-cancer indications by intervention type; PET scans are classified as 'other' and cytoreductive surgery with HIPEC as 'surgical procedure'.

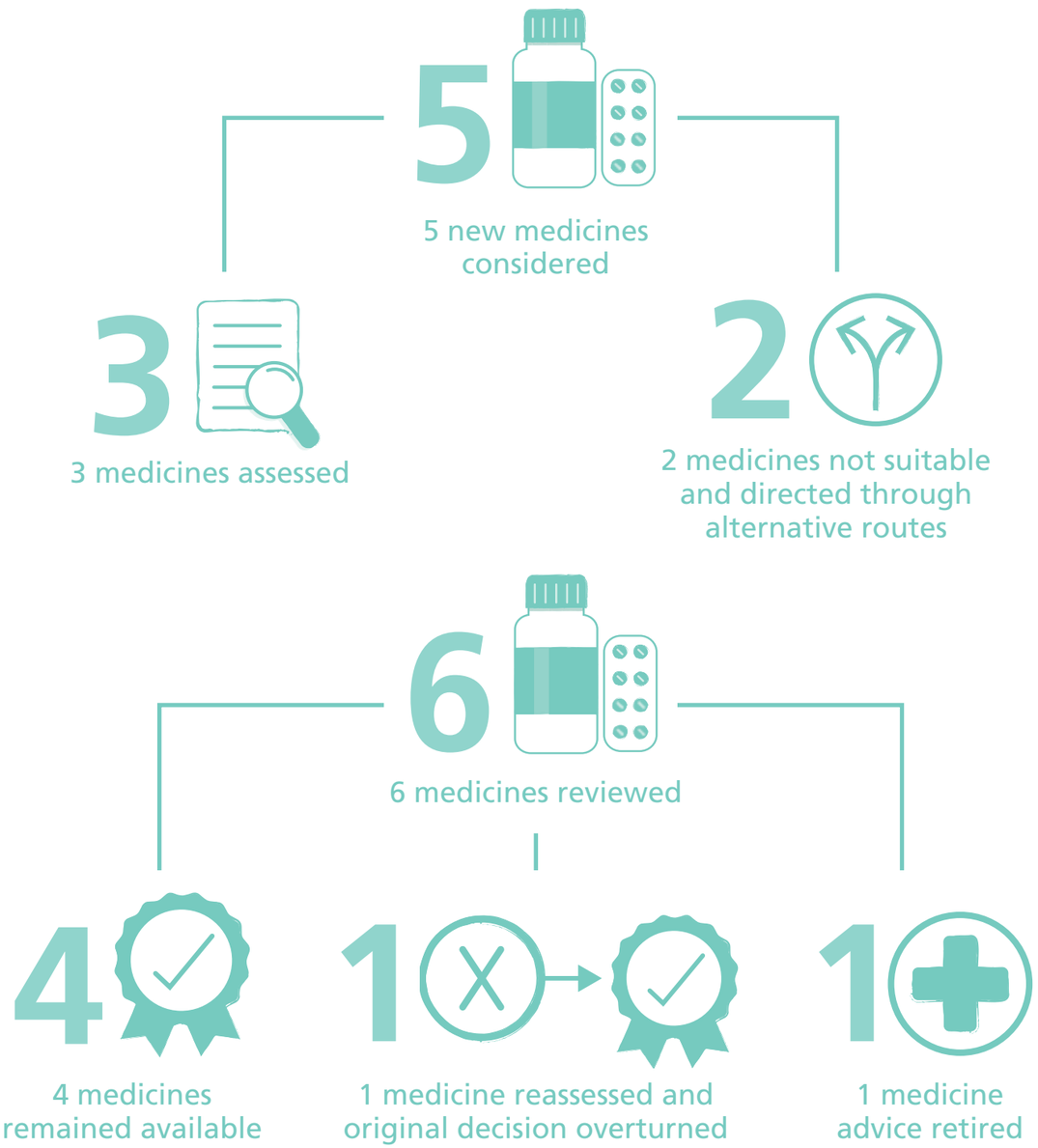
IPFR and the One Wales Interim Pathways Commissioning process

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 Interim Pathways Commissioning process which has been in operation 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 Interim Pathways Commissioning 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 Interim Pathways Commissioning process and current One Wales decisions is available on the AWTTC website (www.awttc.org/pams/one-wales-interim-commissioning-process).

Along with the steady decrease in IPFRs for medicines, emerging cohorts of IPFRs have decreased since the inception of the One Wales Interim Pathways Commissioning process. This trend has continued in 2019/2020 and 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.

Ongoing monitoring of the IPFR data has shown that soon after publication of a positive One Wales Interim Pathways Commissioning 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.

One Wales Interim Pathways Commissioning process activity in 2019/2020



Patient outcomes

Of the data collected during 2019/2020, patient outcome data were available for 39 patients; 36 after applications where the intervention was approved, 2 which were not approved and 1 which was initially approved and then a subsequent continued funding application was not approved. This represents outcome data for 13% of all IPFRs for the year, a similar proportion as reported in 2018/2019.

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

The information provided was inconsistently complete for patients whose treatment was approved. Of the feedback provided, 16 of 25 patients (64%) were reported to have a complete or partial response to treatment and 12 of 19 patients (63%) had an improvement in quality of life. Only basic information was provided for 8 of the patients: all had received treatment and had not died. Where treatment was discontinued no single reason dominated, with disease progression, treatment toxicity and patient choice each accounting for three discontinuations.

Response to treatment

8 Complete response
8 Partial response
3 Disease Progressed
3 Stable disease
3 Not assessable

At time of follow-up three patients had not received the approved treatment. One had made a complete recovery after alternative treatment and the other two had delayed treatment due to co-morbidities and a deterioration in the patient's condition, respectively.

Two patients were reported to have died, one before the approved treatment could be administered and one after disease progression. The two patients for which treatment was not approved were reported to be alive and receiving continued monitoring and continued alternative treatments.

Quality of life following treatment

12 Improved

3 Maintained

4 Reduced

The majority of IPFRs approved in 2019/2020 were associated with evidence of clinical benefit. The number of cases for which outcome data are available in 2019/2020 remains a small proportion of all IPFRs considered.

Reasons for stopping treatment

1 Death
3 Disease progression
1 End of treatment course
3 Patient choice
3 Treatment related toxicity

The collection of outcome data is important to monitor and analyse whether or not a treatment has been effective. AWTTC will continue to work with IPFR panels and clinicians to identify barriers to recording outcomes to provide information on the impact of IPFR decisions in relation to patients.

Quality Assurance Advisory Group

In 2019, quality assurance of the IPFR process showed a continued improvement in outcome measures. Over 90% of IPFRs reviewed met the assessment criteria for applications and panel meetings.

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. In the year 2019/2020, the Group met four times to assess IPFRs covering the 2019 calendar year. Figure 13 shows the percentage of criteria met for each quarter from October 2017 to December 2019. The application process and panel process continued to improve in 2019 with over 90% of IPFRs assessed meeting these criteria each quarter.

The Group is provided with all paperwork associated with a randomly selected IPFR 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 (www.awttc.org/ipfr).

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 to the Deputy Chief Medical Officer and the Head of Pharmacy every six months.

Action points raised last year have resulted in a general continued improvement in IPFRs meeting these criteria in 2019/2020:

- Updated guidance notes for clinicians has resulted in improvement in completion of the statement in support of the application in IPFR forms assessed.
- Improved recording of delays in process and capturing changes in the stipulated urgency resulted in 97% of applications assessed meeting the urgency timelines stipulated.
- Improvements to the recording of panel discussions around value for money in meeting minutes has been seen.
- Considering each case on its own merits. After feedback from the Group last year no panel discussions made reference to previous cases.
- Improvement in clarity as to whether decisions had been reached through Chair's action or virtual panels. There has been an improvement in the minutes provided for all decisions, in particular those made outside the full panel meeting and in terms of the quorum for the panels.

Figure 13: Percentage of IPFRs assessed meeting the Quality Assurance process criteria between October 2017 and December 2019

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The decision process has continued to be followed well overall and over 90% of IPFRs met the criteria in the first half of 2019. In the latter half of the year this percentage fell considerably. This reflects issues in two of the IPFR panel administration teams where staff absence resulted in some tasks falling outside the normal process. In particular, the letters to the clinician and patient were sent later than the five day timeline. However, despite the absence of key staff the core IPFR service was maintained during this time.

Action points for 2020/2021

One action point was raised as an example of good practice shared across the panels. One panel requests that clinicians complete a patient outcome questionnaire as part of a continued funding application. Because there is an ongoing challenge to collect outcome data after IPFR decisions, this was considered a good way to encourage collection.

The Quality Assurance Advisory Group considers that overall the IPFR process was being followed in line with the IPFR policy. The Group was pleased to see improvement in areas highlighted in the previous year as a result of their feedback.

Review of the IPFR Quality Assurance process

In May 2019 the Group held an extended meeting to review the quality assurance process, during which several points were discussed. The discussions and actions are fully documented in the meeting minutes for the May and the August meetings which are available on the AWTTC website (www.awttc.org/ipfr/ipfr-quality-assurance-advisory-group).

Key points from the review:

- The Quality Assurance process should continue to assess one IPFR per panel on a quarterly basis.
- The format of the reports should provide an upfront summary of the findings and recommendations; the rest of the report to remain unchanged.
- It should be arranged for Group members to attend panel meetings as observers, because previous visits had been made before the Quality Assurance Advisory Group was formed.
- AWTTC will align lay member training with the annual IPFR Workshop to support lay members.
- Health Technology Wales (HTW) will provide evidence summaries to support decision making for non-medicine IPFRs.

Overall, the Group thought that the Quality Assurance process was working well to monitor adherence to IPFR policy by all panels and identify any areas where policy was not clear or not followed. The Group will review the Quality Assurance process on a regular basis.

10

IPFR workshop

In May 2019, AWTTC held its fourth IPFR workshop. This annual event was open to IPFR panel members, clinicians who complete applications and those with an interest in learning more about the work of IPFR.

Topics covered during the day included:

- an annual update on IPFRs considered in Wales
- an annual update on the IPFR Quality Assurance Advisory Group
- an introduction to Health Technology Wales (HTW) and ways in which HTW and IPFR panels could work together.

This year the workshop held clinic sessions, where delegates chose to attend three out of five sessions. The sessions were: health economics; legal context; ethical considerations; the role of lay members; and the IPFR database.

"IPFR panel cases were really useful in terms of experience in decision making as part of an MDT panel. The legal session was very insightful and generated healthy discussion within the group."

As per previous years, delegates formed into mock IPFR panels and considered example IPFR cases. The aim of this session was to encourage panel members to share experiences across health boards, develop good practices and demonstrate consistency of decision making. It also provided the opportunity for panel members to network and develop links across health boards.

"I enjoyed the macro-micro IPFRs in the ethics of resource allocation. I especially enjoyed the format of discussions basis surrounding the cases and the clinic sessions."

"Interesting to learn about HTW and how it can help with IPFR. Also cases most interesting and useful."

Colleagues from Welsh Government, AWTTC, Health Technology Wales, Public Health Wales and NHS Wales Informatics Service were in attendance

60 attendees, with representation from each IPFR panel

Summary of the data

Overall the data for 2019/2020 indicate:

A continuing annual decline in the number of IPFRs across Wales since 2015/2016.

The number of IPFRs for medicines increased for the first time since 2013/2014.

37% fewer requests were made for non-medicines compared with the previous year. This decline was driven by a reduction in requests for PET scans as a result of an update to WHSSC's PET-Computed Tomography commissioning policy in June 2019 which included several new indications.

31% more requests for medicines were made compared with the previous year.

72% of IPFRs for non-medicines were approved. This has increased over the last four years, from 49% in 2016/2017.

The number of IPFRs approved has continued to increase year on year for medicines and non-medicines, with 74% of all IPFRs approved in 2019/2020.

78% of IPFRs for medicines were approved. The rate has increased annually over the last five years, from 57% in 2015/2016.

There continues to be a decrease in the number of cohorts created for medicines requested through IPFR.

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Glossary and additional note

AWMSG	All Wales Medicines Strategy Group
AWTTC	All Wales Therapeutics and Toxicology Centre
Continued funding	Funding for treatments previously approved which require an extension to treatment
HTA	Health Technology Assessment
HTW	Health Technology Wales
IPCG	Interim Pathways Commissioning Group
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 its marketing authorisation (product licence)
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 because the potential risk of identifying individual patients becomes significant. Therefore, this information is considered personal information and is withheld under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the Data Protection Act 1998, because 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.