NHS

North West London

Individual Funding Request Annual Report 2011/12

Table of Contents

Section 1 – Executive Summary 4

Section 2 – IFR Background 6

Section 3 – IFR Governance 8

3.1 IFR Standard Applications 8

3.3 IFR Appeals Process 10

3.4 IFR Panel 10

3.5 IFR Signposting 11

3.6 IFR Team 11

Section 4 IFR Outcomes 12

4.1 Summary of Applications Received by PCT 12

4.2 Summary of Applications Received by Intervention 13

4.3 Summary of Applications by Expenditure 15

4.4 Summary of Applications Appeals 16

4.5 IFR Outcomes Policy Development 19

Section 5 – IFR Stakeholders 20

5.1 IFR Stakeholder Feedback Overview 20

5.2 IFR Clinical Stakeholder Feedback – Survey Monkey 20

5.2 IFR Stakeholder Feedback – Patient 21

Section 6 – Conclusions and Recommendations 22

6.0 Conclusion 23

6.1 Recommendations 23

Foreword

The NHS Constitution provides a clear statement for both patients and the NHS that patients have the right "to drugs and treatments that have been recommended by the National Institute for Health and clinical Excellence (NICE) for use in the NHS". However there are some instances when requests are made outside of NICE or similar guidance and the local NHS must have a system in place to ensure:

- There is no outright blanket ban for interventions or treatments
- Must be sensitive to individual circumstances and take account of those circumstances in any decisions
- A system is in place to enable exceptional cases reviews
- Must have robust policies in place which can support clear and defensible decisions on whether access to services will or will not be possible.

NHS North West London established an Individual Funding Request (IFR) in April 2011. This has one central point for the processing and decision making of all IFR applications received across the 8 PCT's.

Bringing 8 different PCT systems into one has not been without its challenges, but this has been outweighed with the benefit, in standardising decision making across a wider population.

This Annual Report covers the work of the NHS North West London IFR Service from April 2011 to March 2012 at comparisons in 2012/13 YTD where this information is available.

June Farquharson
Associate Director IFR Service

Section 1

Executive Summary

In April 2011, the 8 PCT's in North West London moved into one single system for the processing and reviewing of Individual Funding Request (IFR) applications. This in effect has meant bringing eight individual PCT's IFR processes into one.

This annual report covers the first year in operation from 1st April 2011 to 31st March 2012 and provides YTD trend comparisons in 2012/13, where the information is available. The report provides this from a service implementation and application outcome perspective.

Key highlights form service implementation include:

An update on the IFR processes and how the governance to support this has been strengthened. Examples provided include:

- The formalisation of the clinical triage process to ensure a robust system is in place for the assessment of applications before their progression to panel.
- The development of a training programme for IFR panel members in recognition of the pivotal role that the IFR panel play in the process.
- The strengthening of the governance supporting the management of urgent referrals
- The establishment of additional roles within the team to support service delivery.

The report looks at the 1559 IFR applications received in 2011/12 and their outcomes and the report shows:

- Of the 1559 applications received 1245 (68%) went to panel and 842 (67.6%) were approved with an overall expenditure of £4.3m.
- The highest level in terms of applications received and per weighted population (100,000) were from NHS Ealing and the lowest level of applications received from NHS Kensington and Chelsea, but lowest per weighted population was from NHS Westminster. The report provides YTD trend analysis from 2012/13 and finds NHS Ealing continue to have the highest level of applications received but NHS Hounslow, per weighted capitation.
- The highest area in terms of applications approved and expenditure pertain to medicine management cases.
- Of the IFR applications received 436 were for Planned Procedure with Threshold (PPwT) Policy type cases. The IFR applications were received when patients did not meet policy threshold and clinicians put forward an IFR based on exceptionality. The report highlights that a high number of these were for cosmetic procedures and alternative therapies (acupuncture). The applications for acupuncture were from one main acute provider (Imperial).
- Just under half (43%) of PPwT related cases presented to panel are declined due to no clear exceptionality demonstrated. The introduction of robust clinical triage ensures these cases are dealt with before they get to panel.
- There are key benefits of a NWL wide system in identifying patterns of applications and decision making that this should be looked at from a policy development perspective.

- Stakeholder feedback has played a role in the on-going development of the service. This is looked from the clinical stakeholder perspective, based on feedback received from a series of clinical workshops and through the use of the Survey Monkey Tool. An example is provided that shows following feedback adjustments have been made in to the design of the IFR application form.

- Patient satisfaction has been measured using the appeals process as an indicator and key themes that emerge from the patient helpline. This showed 30 appeal cases went to an appeal panel in 2011/12 which represented 14% of cases that were declined. Of the appeal cases heard 86% of the original panel decision was upheld.

Finally the report concludes that 2011/12 saw good progress in the successful implementation of a one single IFR System across North West London which is highly regarded by other London PCT's and will continue to develop under the Commissioning Support Unit. Areas of particularly focus will be an options appraisal to for an IT solution, to provide a higher degree of automation and the establishment of a Policy Development Group.

Section 2

IFR Background

The NWL wide Individual Funding Request (IFR) Service came into effect in April 2011. The IFR service has delegated authority from the 8 PCTs of NW London to process and make decisions for IFR applications up to the value of £50k per case. The IFR Service received 1559 applications in the financial year 2011/12 with 80% of the cases taken to panel for consideration. This report details the developments and activities relating to the IFR service.

Individual Funding Requests (IFR's) are for treatments that are not normally funded by the NHS, or are only funded in certain exceptional circumstances that are reviewed on a case by case basis. Such cases, involving patients with unusual or unique clinical factors, are considered by a panel set up to handle IFR's. The panel comprises of a Chair, Lay Person, Senior Commissioner, Public Health Consultant and Clinical Advisor.

In order for funding to be agreed on the grounds of exceptional circumstances, there must be some unusual or unique clinical factor about the patient that suggests that they are:

- Significantly different to the general population of patients with the condition in question (i.e. compared with the same age-, sex-, disease- specific cohort of patients).
- An example would be an exceptionally indolent or other 'variant' of the illness or host factors such as an unusual genetic make-up that will make them exceptionally responsive to treatment.
- Likely to gain significantly more benefit from the intervention than might be expected from the average patient with the condition.
- An example will be where a treatment is likely to be more cost effective on an individual patient.
- However, the fact that a treatment is likely to be efficacious for a patient is not, in itself, a basis for an exemption.
- If a patient's clinical condition matches the 'accepted indications' for a treatment that is not funded, their circumstances are not, by definition, exceptional.
- It is for the requesting clinician (or patient) to make the case for exceptional status.
- It should be noted that social value judgments are rarely relevant to the consideration of exceptional status.
- The IFR Panel will NOT make a decision to fund a patient where by so doing a precedent would be set that establishes new policy (for example, in situations where the patient is not, in fact, exceptional, but representative of a group of patients). In such cases, if the IFR Panel feels strong evidence has been provided in support of a particular health technology (treatment or intervention); it would make a recommendation to the commissioning directorate to consider the health technology within its planned priority setting and service development process.
- Decisions to fund an exceptional case will not at any time establish precedence even for people with apparently similar conditions.

NHS NWL IFR panel decisions are based on the NHS NWL Ethical Decision Making Framework[i] which is used to demonstrate that the decisions about local health policy are based on sound principles and have been made after careful consideration of all the relevant

factors, with reference to local conditions and with a conscious intent to avoid discrimination. The five key principles of the Ethical Decision Making Framework are that decisions need to be:

- Rational – being logical in the way a reason is applied to reach a decision and ensuring that the decision is based on evidence of clinical effectiveness, benefits to patients and cost.
- Inclusive – Equal opportunity of access to healthcare and patient involvement in the decision making.
- Respectful of individual needs – through a fair and non-discriminatory process.
- Take account of economic factors – resources are finite and must be managed responsibly. policies relating to the NHS NWL IFR Service themselves, and the way they are determined, will be clearly specified, consistent , easy to understand and opened to public scrutiny.
- Promote health for individuals and the community – policies which promote health and avoid people becoming ill are considered alongside curative treatments and other interventions.

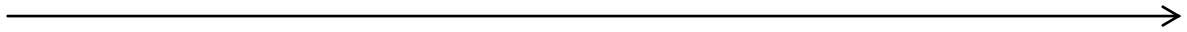
Section 3

IFR Governance

This section of the report provides an update on the service changes made. Throughout 2011/12 there has been a continuous review of the governance framework supporting the IFR process from application to decision making. The NHS NWL IFR Service has four key functions:

- The processing of standard applications
- The processing of urgent applications
- The IFR Panel
- The processing of appeal applications

3.1 IFR Standard Applications



Standard Application Process Timeline

IFR received, administrative triage and acknowledgment sent	Case Logged	IFR Clinical Triage	Case worked up for IFR Panel	IFR Panel	Minutes agreed and decision letters sent
Day1-3				**28 Days**	**5 Working Days**

IFR may be submitted by an NHS consultant, a GP or dental practitioner, or an equivalent autonomous practitioner provided he/she will be responsible for administering the treatment.

Patients may not make applications directly. This requesting clinician is required to affirm that they have discussed the proposed treatment with the patient (or has offered such a discussion) before the application is made for funding on his/her behalf.

The requesting clinician must make the patient aware of the implications of embarking on this process, particularly that it may take some time before the request can be decided and, if the patient is considering privately funding the requested treatment while the IFR is being considered that no retrospective funding is available, even if the IFR is approved.

When an IFR application is received, it goes through a number of validation checks to ensure it is suitable for considerable by an IFR panel. The maximum time from acceptance of an application to panel is 28 days.

During the course of 2011/12 because of the high volume of cases and to ensure the appropriate cases went to panel, governance was strengthened by the introduction of a weekly clinical triage. All new and existing cases are reviewed every week by the GP Medical Adviser and Public Health Consultant. The role of clinical triage is to review the cases received, ensure they are appropriate for panel in terms of exceptionality and ensure they have sufficient information for panel presentation and follow this up when necessary. There are agreed terms of reference for triage and action minutes are taken. The triage system more recently was formally accepted as part of the IFR panel through the Clinical Executive Committee. In terms of governance all triage decisions are ratified by the IFR panel.

3.2 IFR Urgent Applications

In 2011/12, 159 urgent cases were processed which account for 10.2% of the total IFR applications.

Urgent Application Process Timeline

Urgent request received	Clinical reasons for urgency confirmed	Urgent process initiated	Knowledge Manager assigned case	Virtual IFR Panel alerted	Case worked up for IFR Panel	Virtual IFR Panel	Applicant informed of decision
1-2 Working Days		**Day 1 of Urgent Process**				**Days 2-3**	**Day 3**
Daily urgent updates sent to IFR AD, PH Consultant, Knowledge, Ops + Business Managers							

Urgent decisions are made within three working days when an urgent application received has been validated as clinically urgent. Urgent requests are accepted when there is a clear clinical reason why the patient's health would be significantly compromised by waiting until the next scheduled IFR panel meeting for a decision to be made. Trusts who decide to treat before funding approval is granted do so at their own financial risk.

Urgent cases follow the same process as standard applications, including the review of the application by a panel. Because of the turnaround time, this is undertaken virtually, through email.

Because of the high volume of urgent applications and the associated resource required, the governance process surrounding urgent cases has been strengthened, with a clear process for receiving, monitoring and validating urgent referrals. Supporting this is a daily status summary report of all outstanding urgent cases and there status. This also acts as a conduit for escalation when appropriate.

Upon receiving an urgent request, the applicant is contacted to confirm the clinical circumstances regarding urgency and the following decision timescale options are offered:

1. A three working day urgent decision
2. Take to the next available panel
3. Routine 1 month decision

An audit of a 4 week period in 2011/12 revealed that out of the 26 cases that were received marked as urgent, 13 cases (50%) were de-escalated following confirmation that they were not considered clinically urgent or the cases was considered not an IFR (either an NCA or under the cancer pathway). The majority of all de-escalated cases are de-escalated because they are confirmed as not clinically urgent.
The remaining cases are de-escalated because they are confirmed as not IFRs as they fall within contract, are Non-contracted Activity or fall under an existing commissioned cancer pathway.

Urgent decisions are made with reference to the Ethical Framework (NHS NWL Ethical Framework for Decision Making V2.0 Nov 2011) and the consensus method for decision-making, as it is the case for regular IFRs.

3.3 IFR Appeals Process

The IFR Appeals process allows patients and clinicians to appeal against a decision made by an IFR panel. The appeal process must be independent of the IFR process and the panel should meet within 30 days after the acknowledgement that an appeal has been lodged.

IFR Appeal Process

Appeal Application Process Timeline

IFR Appeal received, administrative triage and acknowledgment sent	Case Logged	IFR Clinical Triage Review	Director of Service Review and Appeal Panel Chair	Appeal Panel	Minutes agreed and decision letters sent
Day1-3				**30 days**	**5 Working Days**

The decision of an IFR panel can be appealed on the grounds of:

- Illegality: The Refusal of the request was not an option that could lawfully have been taken by the IFR panel
- Procedural Impropriety: There were substantial and/or serious procedural errors in the way in which the IFR process was conducted
- Irrationality: The decision to refuse funding for the requested treatment was a decision which no reasonable IFR panel could have reached on the evidence before the panel.
- New evidence: additional evidence is provided which amounts to a material difference to the case originally submitted.

The NHS NWL Appeal Panel is chaired by the NHS North West London Chair or other Non-Executive Director, who have not sat on the previous panel. Below is a Chairs perspective on the role of the Appeal Panel

"As panel members, we take into account clinical evidence, and the views of the patient and their doctors. We are very aware of the significance of our decisions for individual patients so aim to be thorough, fair and transparent. The Appeal Panel has used the cases which come before it as learning, to improve the policies, procedures and in some cases to feed back to commissioners. I think this has added value."

3.4 IFR Panel

An essential function in the IFR Service development has been the panel. Panels are held weekly and are made up of a Chair, Lay Person, GP/Clinical Advisor, Public Health and Commissioning support. The Chair of the panel ensures that each case is considered on its own merit and the decision is in keeping with the principles of the Ethical Decision Making Framework.

The role of the lay representative is to provide generic insight from a patient perspective. Lay membership is undertaken on a rota basis and lay members have received on-going

training and support which includes the opportunity to meet collectively as a discipline. Below provides an example of a lay person's perspective contributing to the IFR process:

"I have been a member of the IFR Team now for 3 years, in its various guises. Being on the Panel has been a very rewarding and thought-provoking experience for me. The terminology and language can be of a very technical nature but the clinicians on the Panel ensure that the medical conditions, research and treatment options are explained in simple, everyday language. The role of the lay person is then to give the perspective of the "ordinary person" who at times may see things differently from those in the healthcare profession. I have learnt a huge amount over the last three years about the workings of the NHS and the complexities of ensuring a fair system for all and I look forward to continuing my participation over the coming year."

3.5 IFR Signposting

The NWL IFR Service was established for the 8 NWL PCT's who had previously run individual services which different parameters of scope. The IFR service in 2011/12 received a high volume (12%) of applications that were outside the scope of delegated authority. These applications were sign-posted to existing established services or to individual PCT's. In terms of governance, these were recorded as received and not closed until an acknowledgment sent that the other service had accepted the referral.

3.6 IFR Team

The development of the service in 2011/12 saw the expansion of the team to provide additional capacity to deal with the volume of applications. This was also in line with the Planned Procedures with a Threshold Policy. The additional support was both clinical and non-clinical and this was provided through interim arrangements through the use of agency staff and secondment posts. However in February 2012 a budget paper went to the NHS NWL Board to ensure some of the additional staff changes was more sustainable. An establishment of an IFR Operational Manager role and additional clinical capacity (GP Advisor) and business management support was agreed.

Section 4

IFR Outcomes

Appendix 1 provides a detailed breakdown of IFR applications received by Primary Care Trust in terms of activity and expenditure. This section provides a summary of outcomes for the IFR cases received in 2011/12. It provides this in terms of total applications received and by weighted population. It also provides this by intervention. Where relevant it will make comparative reference to trends identified in cases received in months one to six of 2012/13.

4.1 Summary of Applications Received by PCT

Tables 1&1A below details the total application received by PCT and by weighted (100,000) capitation. This shows that:

- NHS Ealing had the highest level of applications received both in total and per weighted capitation
- Although NHS Hammersmith and Fulham had one of the lowest levels of applications, it was second highest in terms of applications per weighted population
- YTD trend comparison was undertaken on applications received from Months 1-6 in 2012/13 and this demonstrated that NHS Ealing remains the highest PCT in terms of applications received but Hounslow is identified as the highest level of applications per weighted population.

Table 1

RESPONSIBLE PCT	Agreed	Declined	Discharged	N/A	Withdrawn	Grand Total
BRENT TEACHING PCT	121	52	2	28	5	208
EALING PCT	153	98	16	54	6	327
HAMMERSMITH AND FULHAM PCT	80	54	4	18	4	160
HARROW PCT	105	45	1	20	3	174
HILLINGDON PCT	129	29	3	30	2	193
HOUNSLOW PCT	118	58	10	23	3	212
KENSINGTON AND CHELSEA PCT	65	28	2	12	3	110
WESTMINSTER PCT	71	32	3	11	2	119
Grand Total	842	396	41	196	28	1503

Table 1A

RESPONSIBLE PCT	Applications Received	Applications Per 100,000 Population
BRENT TEACHING PCT	208	79.4
EALING PCT	327	97.1
HAMMERSMITH AND FULHAM PCT	160	96.3
HARROW PCT	174	80.1
HILLINGDON PCT	193	74.7
HOUNSLOW PCT	212	87.7
KENSINGTON AND CHELSEA PCT	110	56.7
WESTMINSTER PCT	119	44.8
Grand Total	1503	77.4

4.2 Summary of Applications Received by Intervention

Table 2 below provides a summary of the **top ten non- drug IFR** applications received and their outcomes. This demonstrates that:

- The highest activity level is attributed to acupuncture. The majority of acupuncture IFR forms are received from the pain clinic at Imperial College Health Care Trust. This pain clinic provides the most acupuncture as a modality of treatment. IFR forms are assessed against the NWL complementary therapies acupuncture policy and for cost effectiveness.
- There were also a number of applications received for Stereotactic Radiotherapy/Radiosurgery (SRS/SRT) in 2011/12. The majority of these funding requests were for extra-cranial SRS/SRT for which there is no policy. Cases have to be discussed at the IFR panel and given the volume of cases; this is an area of potential policy/pathway development. This has been raised and discussed with the London Specialist Commissioning Group.

- There are a high number of applications for areas that have an established policy but exceptionality is sited within the IFR application. This primarily includes cosmetic procedures such as laser treatment, scar revision and breast augmentation.
- This is also relevant in areas such as IVF, where there is one agreed policy across NWL for one funded cycle, where previously some NHS NWL PCT's funded more than one. Of those IFR applications received for IVF, 54% of them were declined and for breast augmentation 87% declined both with no basis of exceptionality demonstrated. However YTD trend analysis for Months 1-6 of 2012/13 shows that IVF applications have decreased significantly and it is no-longer in the top 10 interventions. This could be due to the increased awareness of the new policy and less patients in the system who would have been under a previous PCT policy (those with one cycle or more)
- YTD trend comparison undertaken for Months 1-6 of 2012/13 also shows a continued trend with the highest applications being from acupuncture and second highest is for SRS/SRT (Cyberknife), which shows an increased FYE forecast for acupuncture by 65 cases. Both of which will be discussed in the next section in terms of policy development areas.

Table 2 IFR Requests by Intervention (Non Drug)

FUNDING REQUEST / QUERY:	Agreed	Declined	Discharged	N/A	Withdrawn	Grand Total
Acupuncture	97	12		12		121
Laser Treatment	14	27	3	8	1	53
Breast Reduction	19	15	10	2	1	47
Scar Revision	17	19	4	6		46
Stereotactic Radiosurgery Cyberknife	31	1		3		35
Dental Implants	26	6			3	35
Abdominoplasty	7	19	3	4	1	34
IVF	9	18		5	1	33
Breast Augmentation	1	28	3			32
Double Balloon Enteroscopy (DBE)	18					18
Grand Total	239	145	23	40	7	454

Table 3 below shows the top ten medicines management applications received and their outcomes. This demonstrates:

- The two highest drug request and subsequent approvals were for Infliximab and Rituximab
- The majority of **infliximab** requests have been for gastro-intestinal disease -Crohn's and ulcerative colitis. The high numbers are likely to reflect:
    - The ambiguity in NICE guidance for continuation of therapy with a biologic beyond 12 months in Crohn's disease. This has been addressed through the development of the short form now in use across London.
    - changes in clinical practice in managing ulcerative colitis by:
    - attempting to keep patients out of hospital by using infliximab before NICE criteria is met N.B. NICE assumes that people will need admission for 72 hours to receive IV antibiotics for an acute exacerbation of UC
    - Maintaining control of disease by continuing infliximab beyond three induction doses recommended by NICE

- **Rituximab** is licensed in the UK for use in non-Hodgkin's lymphoma, chronic lymphocytic leukaemia and rheumatoid arthritis. The majority of IFRs for rituximab are for rheumatoid arthritis outside of NICE and/or license e.g. for use without methotrexate which is outside of license but has some evidence
    - Its mode of action also means that it is has been used for a number of autoimmune conditions which is borne out in the types of IFR request received e.g. interstitial lung disease due to immune over activity, autoimmune haemolytic anaemia and idiopathic thrombocytopenia purpura. In many cases, compared to alternative treatments rituximab is less costly.
    - Trend comparison with Month 1-6 of 2012/13 shows this trend of top ten drugs continues.

Of note also the majority of requests for **Ranibizumab** (Lucentis) that have been declined have for those patients with:

- diabetic macular oedema to which up until October 2012 NICE had issued a 'not recommended' statement; or
- retinal vein occlusion to which NICE have issued a 'not recommended' in their final appraisal document

Table 3 IFR Requests by Intervention (Medicine Management)

FUNDING REQUEST / QUERY:	Agreed	Declined	N/A	Withdrawn	Grand Total
Infliximab	63	4	5	1	73
Rituximab	47	2	9	1	59
Adalimumab	47	1	8		56
Bevacizumab (Avastin)	34	3	2		39
Ranibizumab (Lucentis)	16	9	3		28
Etanercept	15	1	4		20
Immunoglobulin	14	1	1	1	17
Palivizumab	14				14
Bendamustine	9	4			13
Bone Morphogenic Protein (BMP)	8	1			9
Grand Total	**267**	**26**	**32**	**3**	**328**

4.3 Summary of Applications by Expenditure

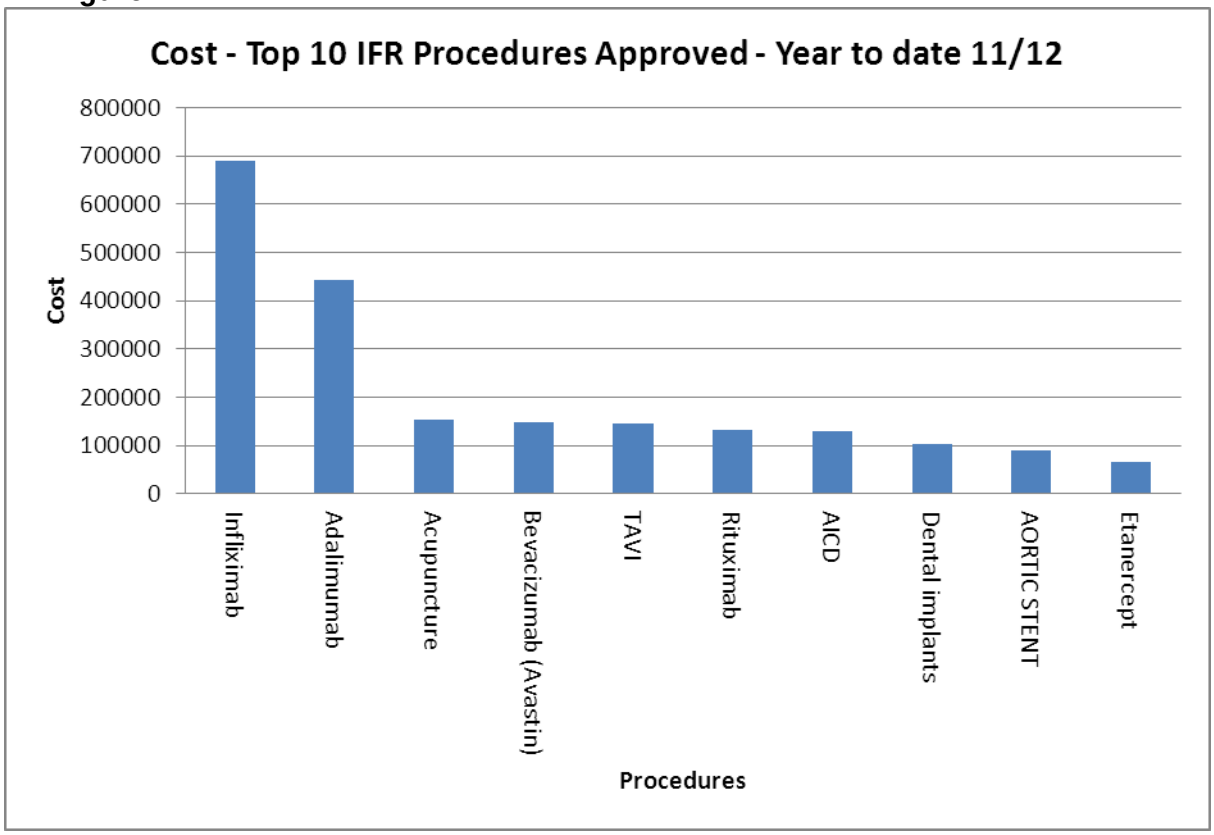
Figure 1 below provides a summary of IFR procedures approved by expenditure in 2011/12. This shows:

- The top two areas of expenditure are related to applications for drug therapies - Infliximab and Adalimumab. The majority of these applications were for inflammatory bowel disease – i.e. Crohn's disease and ulcerative colitis for indications outside of NICE guidance. For example, requests for the continuation of infliximab for Crohn's disease where there is high risk of recurrence or active disease. Most applications were approved. Requests for

Adalimumab were for a wider set of indications and, other than Crohn's, included psoriasis, arthritis and ankolysing spondylitis.

- In 2011/1 applications for Transcatheter Aortic Valve Implantation (TAVI) and Aortic Stent procedures were mainly received from Imperial College Healthcare Trust. These requests were all in line with NICE recommendations, however outside of contracts held with NWL, largely because of the cost of the devices to be used as part of the procedure. In 2011/12 these were processed as IFR applications for panel decision. For 2012/13 a prior notification system is in and applications for such specialised cardiac surgery and devices are considered by our Medical Advisor and not treated as IFRs.

Figure 1



4.4 Summary of Applications Appeals

Table 4 shows the number of appeals lodged out of the 403 cases declined by panel.

This demonstrates that:

- There was overall 60 appeal cases lodged as a result of cases declined at panel which represented 14% of the total declined cases.
- Of those lodged as an appeal 50% (30) were accepted as having sufficient grounds for appeal based on the IFR Standard Operating Procedures Appeal process.
- Of those appeals put forward the Appeal Panel upheld 86% (26) of the original panel's decision.
- Overall 6% (4) of the cases lodged for Appeal were successful.

Table 4 IFR Appeal Applications

Appeals Information	2011-12	% (where applicable)
Appeals	**60**	**4.8%* of total applications**
Appeals taken to Appeal Panel	**30**	**50%**
Appeals approved by appeal panel	**4**	**13.3%**
Appeals declined by appeal panel	**26**	**86.7%**
Appeals not taken to Appeal Panel	**30**	**50%**
Appeals withdrawn	**8**	**26.7%**
Appeals taken back to IFR Panel and approved	**4**	**13.3%**
Appeals taken back to IFR Panel and declined with no further appeal received	**18**	**60%**

Table 5 below provides further analysis in terms of IFR Appeals that are related to PPwT. This shows that:

- of the total appeals received 18 (30%) were as a result of the IFR's received for Planned Procedures with a Threshold that went to an IFR panel and were declined.
- This represented 4% of the overall 186 PPwT related IFR cases that were declined.

Table 5 Appeals Applications by PPwT

	Received	Taken to Appeal Panel	Agreed	Declined
Appeals for PPwT Related Procedures	**18**	**8**	**0**	**8**

4.5 IFR Outcomes Policy Development

During the course of the year, one of the key benefits of a NWL wide IFR Service is the ability to identify patterns of applications from particular providers and raise these with contracting teams as this should be raised contractually by a provider as a Service Development request. These trends often also extend to the basis of IFR panel approvals and therefore are identified as areas of potential policy development – to ensure standardised decision making. This information could also be used to inform policy at a strategic level.

Appendix 2 shows areas that have been identified - key highlights include:

- A number of IFR applications have been received and taken to panel for SRS/SRT (Cyber-knife). These received from Mount Vernon, Royal Marsden and Private Providers. There are a number of requests that have been received requesting Cyberknife as a treatment option for a wide variety of indications, some of which with more evidence than others. However, it is not currently part of the commissioned pathway with the Specialist Commissioning Group and therefore present as IFR's. The IFR Service has shared this data with the London Specialist Commissioning Group to help inform the Cyberknife review.
- In light of the high volume of acupuncture IFR applications, a review of the NWL complimentary medicine policy will be required.
- There has been a number of Biological Meshes for abdominal wall repair's received from one provider, with 9 out of 10 of them being approved for basis at IFR panel. The Royal Free has agreed this with their host commissioners (NHS North Central London). It is recommended that NHS NWL undertake an evidence base review with a view to developing a policy.
- There were 19 Double Balloon Enteroscopy IFR applications received and approved in 2011/13 all for the same indications for patients whom it had not been possible to pinpoint the source of bleeding or where investigations and treatment is intended to be done at the same time.
- A number (24) of IFR applications have been taken to panel for Trans aortic Valve Implantation (TAVI – high cost cardiac devices. Requests are representative of cohorts of patients who cannot have open valve replacement procedures.

It is proposed the review of areas highlighted is undertaken through the establishment of a Policy/Funding Development Group. The role of the Policy/Funding development group is to ensure there is a robust governance framework to support prioritisation, sufficient evidence review and clear recommendations for consideration by Clinical Commissioning Groups.

Section 5

IFR Stakeholders

5.1 IFR Stakeholder Feedback Overview

Stakeholder feedback has played a key role in on the on-going development of the service. The IFR service has used a number of methods to gain feedback from internal stakeholders, including General Practitioners, acute clinicians and managers. This feedback has been received from:

- Survey Monkey is an online tool that allows the user to very quickly create, customise and distribute surveys. The service is based online and is completed by the user via a web based form.
- Borough based review workshops, which included representation from acute clinicians/managers, Clinical Commissioning Group clinicians, and commissioners. These workshops were used to gain feedback and provide clarity on both the IFR and Planned Procedures with a Threshold Process.
- The development of a dedicated email address which is used by clinical stake-holders to ask advice on the completion and processing of the application

5.2 IFR Clinical Stakeholder Feedback – Survey Monkey

Table 6 below is an extract based on the clinical feedback received from using Survey Monkey on the IFR process and application.

Table 6 Clinical Stakeholder feedback

Provider/GP	Feedback
GP	• As a GP I still have some concerns about appropriately filling this out, and feel we need clear guidance on who should and who should not fill this in. • I appreciate that you need the answers to the questions below but I think they our outside of the GPs expected knowledge: Is it part of a clinical trial • Specific Patient severity score • Published data recommending the intervention • Who will monitor the effectiveness of the intervention • Any anticipated or likely adverse events • Successful outcome measures • These questions are vital really for you to approve funding but not necessarily appropriate to be completed in primary care.
Provider	• Seems an improvement on the previous one. • Our pharmacists feels the form requires more sign posting to help direct busy clinicians to the relevant section within the document this is one example. After box 26 say go to section 8 • 'If all clinical information is submitted the IFR Team will endeavour to provide a funding decision by 1 month' - Previously the response to IFR requests was 28 days, we feel it would be useful if this was more specific. • In part 1 no. 2 giving a GP name these days shouldn't be required; indeed many of us don't have a named GP, so 'registered GP practice should suffice'. • May need to adapt form in line with older software due to formatting but otherwise it seems fine – and similar to current ones.

- Some clinicians felt it was also still inflexible, but not all. Further work is required to communicate to clinicians which are the relevant sections for them to complete.
- Nearly all those who responded about the form highlighted the need for Primary Care to complete the relevant sections prior to referral. This will save time in processing referrals and not having to request further information.
- Many of the respondents felt this version was easier than the current version to use.
- Discussion about having a specific cosmetic surgery version of the form that they have drafted and is attached within the email.

5.3 IFR Clinical Stakeholder Feedback – Clinical Workshops

All providers during 2011/12 had six month review meetings for IFR and PPwT. The IFR process was discussed as part of the agenda. The overall key messages

- That the IFR form was designed for complex medical cases and that there was a need to re-design the referral form to meet the needs of all referrers.
- There was recognition that some IFR's required a multidisciplinary approach for completion and would therefore need input across primary and secondary care
- Manual completion of the form was time-consuming

A key theme that derived from the feedback was the style of the application form. Based on the feedback a new application form was developed and trialled with clinical stakeholders before full roll out in July 2012.

A Provider Service Specification was also produced for provider organisations to provide a summary on the IFR process and the role of the referring clinician.

5.4 IFR Stakeholder Feedback – Patient

Whilst no formal methodology has been used to gain patient feedback two main indicators are used as a measure of patient satisfaction.

In 2011/12, the IFR Service received 4.8% of appeals as a percentage of the total applications received and 14% as a percentage of the total applications that were declined at IFR Panel. The IFR Appeal process provides an independent platform for appealing an original IFR decision. This can be instigated by the patient, preferably with clinical endorsement. As part of the NWL IFR Service Appeals Terms of Reference, patients are given an opportunity to come and present to the IFR Appeal Panel the impact from patient perspective. Of the 30 Appeals cases held 5 patients have made representation at panel.

The other indicator used to measure patient satisfaction is through the dedicated patient helpline. The patient helpline was established to provide patients with support through the PPwT and IFR process by providing guidance and policy advice. The most common queries received by the helpline are:

- General process e.g. timescales and status of PPwT/IFR requests received
- Cosmetic PPwT/IFR requests such as Abdominoplasty / PIP Implants

- IVF policy information (number of cycles available) and criteria information
- Healthcare abroad information on process and what treatments are available.
- A common misconception is that the funding process includes the booking of appointments. The NWL IFR team are not an appointment service but always endeavour to assist patients by guiding them to the correct place to query appointment bookings.

As a proxy to gauge patient satisfaction, we can consider PPWT's that convert into IFR's and ultimately end up as lodged appeals.

During 2011/12, 436 PPwT cases were presented as IFR's. Of this number 186 (43%) cases were declined and 18 (4%) cases were subsequently lodged as an appeal. 8 (1.8%) of these were considered by the Appeals Panel and the original decision was upheld in all cases. There were no complaints or requests for further review following the appeal decisions.

Section 6 – Conclusions and Recommendations

6.0 Conclusion

This report has provided an overview of the NHS NWL IFR Service in the first year of operation. It has discussed the governance operating framework and has also provided a summary in terms of outcomes applications received. It has shown that the largest area of applications and expenditure pertains to medicines management.

The report has described the system for the receipt, processing and decision making of individual funding requests across the whole of North West London and this has benefits in standardising decision making, both across the population and the portfolio of providers.

The report has looked the development of the service from a stakeholder perspective and shown when feedback from clinical stakeholders has been used to change the layout of the IFR application form.

On the publication of this annual report, the service has in fact been operational for 18 months and in the annual report for 2012/13 there will be the ability to provide benchmarking data on comparative activity and cost expenditure across the Clinical Commissioning Groups.

The local Clinical Commissioning Groups have indicated that this is a service that it wishes to procure as part of the Commissioning Support Unit product offering and as the service continues to develop, there are some key service development areas that would need to be considered for it to be sustainable including a management information system.

The report has highlighted that the service has made good progress, particularly in strengthening its internal governance processes, with the introduction of clinical triage. It has also highlighted that the IFR service in its first year has also provided a platform for signposting to establish commissioned pathways and services and has produced commissioning intelligence that could be used for identifying policy development areas. This could also be used to identify when provider trusts should be submitted applications for service developments rather than using the IFR application route.

6.1 Recommendations

The Board are requested to:

- Note the service progress made
- Note and discuss the IFR applications outcomes and identify further analysis required.
- Agree the recommendation of developing a business case for a proposed integrated IT solution with an online portal for IFR case submissions and tracking. This will further strengthen the IFR governance framework.
- Agree the recommendation of an establishment of a Policy Development group to take forward the areas highlighted in section 4 as part of the 2013/2014 Commissioning Intentions.

[i] NHS North West London Ethical Framework for Decision Making V2 Nov 2011