ALL WALES IPFR POLICY: EqIA Response August 2011

INTRODUCTION

In response to guidance from the Welsh Government, NHS Wales has developed an All Wales Policy for Individual Patient Funding Requests (IPFR). As part of this development, an equality impact assessment was completed and a wider public engagement exercise undertaken during July and August 2011 on the issues arising from the assessment. This response addresses the equality issues raised during this engagement.

MEETING THE PUBLIC SECTOR EQUALITY DUTY

Under Section 149 of the Equality Act 2010, health boards are required to demonstrate that they have paid due regard to the need to:

- eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Act;
- advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
- foster good relations between persons who share a relevant protected characteristic and persons who do not share it..

In addition, under Regulation 8 of the Equality Act 2010 (Statutory Duties) (Wales) Regulations 201, health boards are required to make arrangements to assess the likely impact of a proposed policy on their ability to comply with this general duty.

FEEDBACK FROM THE EQUALITY IMPACT ENGAGEMENT

The feedback received during the engagement period is enclosed at the end of this document. This feedback addressed some equality issues but also provided comments on the merits of the policy itself. Some of these comments are very helpful and so have also been included here.

EQUALITY IMPACT

The specific equality issues raised can be grouped under 4 headings and these are discussed below.

Issue 1: Considering Social Factors when Making Decisions on Requests for Treatment

Many of the responses focused on the decision making factors and whether social factors would be considered when assessing exceptionality under the policy. For example, a GP expressed concern that religious or cultural beliefs could result in clinical treatments being undertaken for non-clinical reasons.

The policy is clear that social factors will not be considered in decision making and that decisions will be reached on an assessment of clinical need. This approach required consideration to ensure that it did not directly or indirectly create disadvantage – recent caselaw in an England NHS case finds that this approach is intentionally non-discriminatory, as explained below:

The Court of Appeal recently found in R (on the application of Alexander Thomas Condliff) and North Staffordshire Primary Care Trust (where social considerations were excluded) that:" the policy of allocating scare medical resources on a basis of the comparative assessment of clinical needs is intentionally non-discriminatory. The statutory function of the (PCT) is to use the limited resources provided to it for the purposes of the provision of

healthcare, i.e. services in connection with the prevention, diagnosis and treatment of illness. To perform that function by allocating those resources strictly
according to the PCT`s assessment of medical need i.e. an assessment based on clinical factors, is to do no more than to apply the resources for the purpose for which they are provided without giving preferential treatment to one patient over another on non -medical grounds."

ACTION: The policy reference to the consideration of social factors will be amended to include the above information so that patients and clinicians are
aware that this aspect has been fully considered and that the policy is consistent with the recent decision of the Court of Appeal.

Issue 2: Impact of Exceptionality

Again, many of the responses raised the impact of 'exceptionality' for specific groups of patients. For example, the Rarer Cancers response and that of
Genetic Alliance UK questioned how individuals with rarer cancers would be accommodated within the policy and whether the concept of exceptionality as
expressed would discriminate against them as a specific cohort within cancer patients. It was suggested that the exceptionality criteria should be relaxed to
accommodate the potential disability status of those with rarer cancers.

It would be inappropriate to apply differential definitions of exceptionality to different groups of patients. The clinical decision making factors in the policy
focus on an assessment of individual clinical need and the ability for an individual patient to benefit from a treatment. Since the rarity of a condition is clearly
relevant in this assessment as is the level of evidence available to support the use of a drug in specific circumstances, the policy is not currently considered
to be potentially discriminatory in this regard

ACTION: The implementation of the policy will be routinely monitored by individual health boards to assess the impact of decisions on specific groups of patients. Should concerns arise, these will be immediately raised with the Welsh Government and other health boards and will trigger a review of the policy.

Issue 3: Conflict between Ethical Considerations and the Rights of the Individual

Some responses raised whether there was an ethical conflict between balancing the needs of the population with the rights of individual patients. Decisions
could contravene individual human rights.

In the same case referenced for issue 1, the Court also found the PCT had similarly grappled with the difficult ethical and practical questions involved in
settling its IFR policy. In arriving at that policy, the Court found that the PCT has struck what it considers to be a fair balance between the interests of

individuals and the community (for example, whether patients who are carers should have priority over others) and a fair balance between different patients
with similar conditions. The PCT was entitled to set an IFR policy which reflects what it reasonably considers to be the fairest way of treating such patients.
This led the Court to conclude that " nothing in the authorities therefore leads me to conclude that the policy of the PCT, properly understood, is to be regarded as showing a lack of respect for Mr Condliff`s private and family life, so as to bring Article 8 into play. If, however, Article 8 is applicable, there were
legitimate equality reasons for the PCT to adopt the policy that it did and its decision was well within the area of discretion of margin of appreciation properly
open to it."
Following consideration, it has been concluded that operation of the policy should not lead to an interference in an Article 8 right.
NO ACTION IDENTIFIED
Issue 4: Access to the Policy
The majority of responses raised the need for clearer references to advocacy support for patients within the policy. This is accepted.
ACTION: Improve the reference to the ability for patients to access advocacy support, both to understand the policy and also to undertake the application and review processes.

WIDER COMMENTS ON THE POLICY AND ITS IMPLEMENTATION

Communication: health boards will ensure a communication programme for IPFR in their areas

Training: training for panel members will be provided

Support for Clinicians in Making Applications: IPFR teams in health boards can assist with making applications

Lodging an Appeal: the wording of section 7.4 will be amended to read " a review should be lodged with" and section 7.2 then provides the information on
who can lodge the appeal

Introducing New Medicines: the mechanism for assessing the introduction of new medicines is NICE or AWMSG - the IPFR Policy is designed to deal with
requests for medicines to be provided outwith the NICE or AWMSG position - it does not deal with cohorts of patients, but individual patients on an exceptional basis

Restrictions on Applications: patients with their clinicians are free to make IPFR requests in line with the policy

Requirements for Patients to Sign Applications: legal advice is clear that patient knowledge and acceptance of the IPFR is required, however the form has
been amended to overcome the valid issue raised of potential delays and a need for further clinic attendances to acquire signatures

Publishing Decisions: an annual audit report may well prove valuable, including discussion of the requests that were screened out and what was

considered by the panels – however it should be noted that maintaining patient confidentiality will impact on what information is published

Naming Panel Members and IPFR Officers: panel members and officers will be named – although on the clear expectation that they are not personally
targeted by patients and their families when collective decisions are made not to support treatment requests

CONCLUSION

Taking into account the issues raised during the engagement period and the principles established by very recent caselaw, health boards are satisfied that
the policy is not discriminatory in itself and indeed, in light of the careful consideration which has been carried out and the supporting evidence, it is a positive step towards securing fair access to resources.

APPENDIX: Feedback Received by Health Board

Health Board Comments

Abertawe Bro

Morgannwg

From a range of community / staff engagement events

"we need more engagement events in order to raise further awareness and allow people to understand the policy - this needs to be done via smaller groups and targeted communications"

"there needs to be a Wales-wide training package for those lay members that sit on the decision panels"

the CHC will be holding a national meeting on 8th August to discuss the role of lay representatives on the decision panels and the involvement of the CHC in general

"Can organisations outside of the NHS make applications to provide specialist services for patients?"

"What processes are in place with regards support for GP's to complete applications"

"How many applications on average to you receive per year"

"what is the Health Board doing to make their staff aware of the IPFR process, so that they can inform patients and carers"

"what will the Health Board do to address issues with specific needs in a particular area, where the commissioning of a localised service or service level agreement to provide that service would be more beneficial"

it would be good to have similar awareness raising events for staff to allow clinical discussion.

Aneurin Bevan " A patient who wishes to request a review should lodge their request with the IPFR Coordinator of the health board, within the review period. The documents lodged must include the following information:

The aspect(s) of the decision under challenge and

The detailed ground(s) of the review request.

I think this could be construed by a patient that he/she can request a review in isolation. I accept that 7.2 precedes and clarifies this but the two could lead to confusion for the patients. All it needs is a simple alteration to say: A patient who wishes to request a review, with the support of their clinician, should lodge .... "

Powys From a GP

I write as a GP principal. I have two main points to make:

Firstly, the decision-making process relating to refusing requests for bariatric surgery have seemed perverse in the face of NICE guidance on the overall financial benefits and cost-savings of the surgery rather than the increased social care needs of people otherwise severely limited and likely to need increasing health and social care. The refusals have seemed to ignore local GP

knowledge of patient circumstances. I am concerned at the human rights impact of these decisions on patients' human rights to life.
My second point relates to IPFR for religious or cultural reasons. I support an evidence-based, quality health service premised on principles of equality, child protection, and human rights. No one person's demand for special treatment should seriously damage another person's human rights. I would urge the decision-makers to bear in mind that some supposedly reasonable requests for IPFR may cause serious harm to other people. I refer to requests for ritual or religious genital surgery on boys, sometimes known as non-therapeutic male circumcision. Evidence for the harm of this procedure is being increasingly recognised. My main concern is that it frustrates the rights of boys to make their own decisions about permanent changes to their own bodies simply in order to satisfy another person's religious views. The boys themselves will later be in a position to determine whether or not they wish one of the most sensitive (Sorrells et al 2007 BJUI 'Fine Touch Pressure Thresholds in the Adult Penis') and private and intimate parts of their body to be surgically excised because of their parents' views. Until such time, requests for surgery on another person's body should be dealt with in a similar way to requests for facial scarification, tattooing (Tattooing of minors Act 1969) or FGM and should always be refused on ethical ground

I am concerned that the current scoring table does not take account of certain areas which should provide either blanket refusal such as this or immediate acceptance. Requests for non-therapeutic surgery on the body of a non-consenting person should always be refused with no further consideration required. This is basic child protection. I am pleased that current WAG policy seems to support this view and would strongly endorse it.

Cardiff and Vale From an Oncologist, Velindre NHST
There is need for clarity regarding multiple applications for new cancer drugs (for example, everolimus in kidney cancer). In this situation a whole cohort of patients may benefit from the drug, and the whole cohort is 'ipso facto' exceptional. We find in these situations that most patients are declined, but occasionally a request is granted, apparently in a random fashion.
We are frequently asked by Health Boards not to refer these patients, but this has never been in writing….. What is our legal position if we reluctantly take this advance (against our clinical judgement). Why does this policy avoid dealing with this issue ?

From a Consultant Dermatologist at UHW
The policy is very comprehensive and well written. I would like to make 2 observations:
1. NICE and All Wales Medicines Strategy Group approved treatments does not need request through IPFR. Hence there is scope for simplifying the application by removing these sections.
2. In the new document do we need signature of the patient as well? If yes this will cause inconvenience to patient and delay in the application process. At least in dermatology, the patients are seen in the clinic and application is made subsequently after collecting evidence. If the patient has to come back to sign the application, it will involve using additional resource

(time, travel expenses, loss of work time.)

From ABPI Wales From Medlaw EU

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