

Report of the Evaluation of the Individual Funding Request Process

Consultation Response Questionnaire

CONSULTATION RESPONSE QUESTIONNAIRE

You can respond to the consultation document by e-mail, letter or fax.

Before you submit your response, please read Appendix 1 about the effect of the Freedom of Information Act 2000 on the confidentiality of responses to public consultation exercises.

Responses should be sent to:

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Responses must be received no later than 08 May 2015

I am responding: as an individual
on behalf of an organisation
(please tick a box)

<input type="checkbox"/>
YES

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Background

The Minister for Health Social Services and public launched an evaluation of the Individual Funding Request (IFR) process for specialist drugs on 24 September 2014.

This evaluation was intended to provide a rapid assessment of the existing IFR process and to make recommendations as to whether the IFR should continue in its current form or whether a new process should be considered.

The report of the evaluation was published by the Health Minister Jim Wells on 17th February 2015. It sets out 5 recommendations which refer to a range of areas across the health service in Northern Ireland. The full report can be accessed at:

www.dhsspsni.gov.uk/

Purpose

This questionnaire seeks your views on the recommendations arising from the evaluation and should be read in conjunction with the full report.

The consultation questionnaire

The questionnaire can be completed by an individual health professional, stakeholder or member of the public, or it can be completed on behalf of a group or organisation.

Part A: provides an opportunity to answer questions relating to specific recommendations and/or to provide general comments on the recommendations.

Part B: provides an opportunity for respondents to give additional feedback relating to any equality or human rights implications of the recommendations.

When responding to Part A please indicate which recommendation(s) you are providing feedback on:

Please tick which recommendations you are providing feedback on	
Recommendation 1 – Revising the existing exceptionality criteria	YES
Recommendation 2 – Establishing regional scrutiny committee(s)	YES
Recommendation 3 – Increased transparency	YES
Recommendation 4 – Establishment of a Special Medicines Fund	YES
Recommendation 5 – Re-introduce prescription charges to resource the Fund	YES
General Comments	

Part A
Feedback on Recommendations

Recommendation 1

That the existing exceptionality criteria should be amended to remove the reference to 95%.

It is recommended that a new definition of clinical exceptionality should be developed that is clearly understood by patients and their clinicians, families, carers and representatives and is fully explained as to how it should be applied both at Trust level and at Commissioner level and the interdependency between the two.

Q1. Do you agree that the current exceptionality criteria are too high?

Strongly agree Agree ——— Neither ——— Disagree ——— Strongly disagree

Comments:

Yes there needs to be in-built flexibility on decision making based on a patient's clinical need.

Recommendation 2

That the establishment of regional scrutiny committees should be considered to ensure all IFR applications are subject to regionally consistent clinical input and peer review.

It is recommended that a regional group (or groups to cover the clinical specialities which use specialist drugs) be established to meet weekly which will allow for the consideration and clinical endorsement of IFR applications from all Trusts.

Q1. Do you agree with this recommendation?

Strongly agree Agree ——— Neither ——— Disagree ——— Strongly disagree

Comments:

This would ensure swift decision making for the benefit of patients. This must be followed through by equally swift decisions being taken by Commissioners and timelines should be set for this part of the process too.

Recommendation 3

That the existing IFR guidance should be revised to include greater transparency.

It is recommended that the Department working in partnership with the HSCB, HSC Trust and the Patient Client Council (PCC) should conduct further work with clinicians and patient representatives to ensure that there is absolute clarity regarding the process itself and professional roles. This work should also consider the collection and recording of data relating to specialist treatments.

Q1. Do you agree that the process would benefit from a greater level of transparency?

Strongly agree Agree ——— Neither ——— Disagree ——— Strongly disagree

Comments:

Transparency and clarity are essential to build patients' trust in the process. There should also be clear pathways for patients and their advocates to challenge any decisions made.

It makes sense to have systems in place that will improve the collection and recording of specialist treatment data as this will improve decision making, help monitor parity of access, help inform service provision and budget needs and would provide a benchmark for coming years.

Q2. Do you agree that increased transparency would have a positive impact on patients' and clinicians' confidence in the process?

Strongly agree Agree ——— Neither ——— Disagree ——— Strongly disagree

Comments:

Confidence in the process is essential and helps ensure parity of decision-making and helps maintain important relationships between patients and their doctors.

Recommendation 4

That the Department should establish a Specialist Medicines Fund to meet the costs of administering and maintaining increased access to specialist drugs.

It is recommended that the Department should establish a new Specialist Medicines Fund to support the changes proposed here and to ensure that funding for these medicines and the infrastructure necessary to support them is put on a secure financial footing.

Q1. Do you agree that the Department should establish a Specialist Medicines Fund to put funding for medicines on a secure financial footing?

Strongly agree Agree Neither ——— Disagree ——— Strongly disagree

Comments:

Options over than revenue raised by prescription charges should be explored for supporting the availability of specialist medicines. The Public Accounts Committee report on Primary Care Prescribing highlights the potential for significant savings to the health service without affecting patient care. The pharmaceutical industry also point to the Pharmaceutical Price Regulation Levy, used to fund specialist medicines in Wales and Scotland, as an available source, which would exceed the amount required.

Recommendation 5

In order to resource the new fund, the Department should re-introduce charging for prescriptions.

In view of the current financial position, and the need to invest in services such as the provision of new specialist drugs, this is an appropriate time to reconsider the provision of free prescriptions in Northern Ireland. The additional funding provided through this would be used to put funding for specialist medicines on a secure financial footing.

Q1. Do you agree that it is reasonable for patients to make a contribution towards the costs of their prescriptions, particularly in light of the challenges of funding high cost specialist medicines?

Strongly agree ——— Agree ——— Neither ——— Disagree Strongly disagree

Comments:

PID UK supports the Prescription Charges Coalition response to this consultation.

PID UK supports people affected by primary immunodeficiency (PID), rare genetic conditions that are associated with long-term chronic health problems. As a member of the Prescription Charges Coalition PID UK feels strongly that everyone with one or more long-term condition should be exempt from charges wherever they live in the UK. We are aware that the financial burden of prescription charges may prevent patients in financial hardship from seeking the important medical attention they need and cause them to ration their drugs, leading to increased morbidity with a total greater cost to the NHS than the economic burden of free prescriptions. Eliminating charges for chronic life-long conditions that require replacement therapies such as PIDs would remove this barrier and provide fairness of access to medicines across all the four home nations in the UK.

Other options should be explored for supporting the availability of specialist medicines and it is not appropriate, reasonable or fair to do this at the expense of those with long-term conditions.

Q2. What do you consider would be the most appropriate way to apply such a charge?

Comments:

PID UK does not believe it is right to apply such a charge and we have serious concerns about the inclusion of proposals relating to the reintroduction of prescription charges within this review of access to specialist medicines.

Any further consideration of the reintroduction of prescription charges should only be done after a full assessment of the potential health outcomes, including the impact on those with long-term conditions and organisations representing people with long-term conditions and health professionals should be involved in discussions relating to these. Many other people will be affected and disadvantaged by the reintroduction of charges because they simply cannot afford the medicines. This in turn will lead to poor health, an increase in days off work, and potential increases in cost to the health system due to increased hospital admissions. Because of this PID UK would like to see a thorough and wide ranging economic impact assessment.