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:

E-mail: IFRPC@dhsspsni.gov.uk

Written: IFR Evaluation Consultation
        DHSSPS
        Room 1
        Annex 1
        Castle Buildings
        Stormont Estate
        Belfast, BT4 3SQ

Tel: (028) 9052
Fax: (028) 9052

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)

Name: ________________________________

Job Title: ________________________________

Organisation: ________________________________

Address: ________________________________

Tel: ________________________________

Fax: ________________________________

e-mail: ________________________________
Contents

<table>
<thead>
<tr>
<th>SECTION</th>
<th>Page No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td></td>
</tr>
<tr>
<td><strong>Part A – Feedback on Recommendations</strong></td>
<td></td>
</tr>
<tr>
<td>Recommendation 1 - Revising the existing exceptionality criteria</td>
<td>6</td>
</tr>
<tr>
<td>Recommendation 2 – Establishing regional scrutiny committee(s)</td>
<td>8</td>
</tr>
<tr>
<td>Recommendation 3 – Increased transparency</td>
<td>9</td>
</tr>
<tr>
<td>Recommendation 4 – Establishment of a Special Medicines Fund</td>
<td>10</td>
</tr>
<tr>
<td>Recommendation 5 – Re-introduce prescription charges to resource the Fund</td>
<td>11</td>
</tr>
<tr>
<td>General Comments</td>
<td>12</td>
</tr>
<tr>
<td><strong>Part B – Equality Implications</strong></td>
<td></td>
</tr>
<tr>
<td>Appendix 1 – Confidentiality of Consultations</td>
<td>16</td>
</tr>
</tbody>
</table>

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:
<table>
<thead>
<tr>
<th>Please tick which recommendations you are providing feedback on</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendation 1 – Revising the existing exceptionality criteria</td>
</tr>
<tr>
<td>Recommendation 2 – Establishing regional scrutiny committee(s)</td>
</tr>
<tr>
<td>Recommendation 3 – Increased transparency</td>
</tr>
<tr>
<td>Recommendation 4 – Establishment of a Special Medicines Fund</td>
</tr>
<tr>
<td>Recommendation 5 – Re-introduce prescription charges to resource the Fund</td>
</tr>
<tr>
<td>General Comments</td>
</tr>
</tbody>
</table>
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?

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
</table>

Comments:

Q2. Do you agree that it is right to retain the concept of exceptionality within the IFR process?

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
</table>

Comments:
Q3. What would be an appropriate definition of exceptionality?

Please complete the box below

Comments:
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?

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
</table>

Comments:

Q2. If you do not agree, can you suggest another method of ensuring regional consistency?

Comments:
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?

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
</table>

Comments:

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

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
</table>

Comments:
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?

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
</table>

Comments:

[Blank field for comments]
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:

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

Comments:
**General Comments**

Please use the box below to insert any general comments you would like to make in relation to the recommendations or wider content of the evaluation report.

<table>
<thead>
<tr>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
Part B
Equality Implications

Section 75 of the Northern Ireland Act 1998 requires the Department to “have due regard” to the need to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and women generally; between persons with a disability and persons without; and between persons with dependants and persons without. The Department is also required to “have regard” to the desirability of promoting good relations between persons of a different religious belief, political opinion or racial group.

The Department has also embarked on an equality screening exercise to determine if any of these recommendations are likely to have a differential impact on equality of opportunity for any of the Section 75 groups. We invite you to consider the recommendations from a section 75 perspective by considering and answering the questions below. Answering these questions will contribute to the completion of the Department's Screening template and the screening outcome.

Q1. Are the actions/proposals set out in this consultation document likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the Northern Ireland Act 1998? If yes, please state the group or groups and provide comment on how these adverse impacts could be reduced or alleviated in the proposals.

Yes [ ] No [ ]

Comments:
Q2. Are you aware of any indication or evidence – qualitative or quantitative – that the actions/proposals set out in this consultation document may have an adverse impact on equality of opportunity or on good relations? If yes, please give details and comment on what you think should be added or removed to alleviate the adverse impact.

Yes  [ ]  No  [ ]

Comments:

Q3. Is there an opportunity to better promote equality of opportunity or good relations? If yes, please give details as to how.

Yes  [ ]  No  [ ]

Comments:
Q4. Are there any aspects of these recommendations where potential human rights violations may occur?

Yes ☐  No ☐

Comments:

Please return your response questionnaire. Responses must be received no later than 08 May 2015
Thank you for your comments.
Appendix 1

FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. Before you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case. This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation. However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor’s Code of Practice on the Freedom of Information Act provides that:

- the Department should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Department’s functions and it would not otherwise be provided

- the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature

- acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner

For further information about confidentiality of responses please contact the Information Commissioner’s Office (or see web site at: http://www.informationcommissioner.gov.uk/).