

REVIEW OF PAEDIATRIC HEALTHCARE SERVICES IN NORTHERN IRELAND (PHASE 1 AND 2):

CONSULTATION RESPONSE QUESTIONNAIRE ON A DRAFT REVIEW OF PAEDIATRIC HEALTHCARE SERVICES PROVIDED IN HOSPITALS AND THE COMMUNITY

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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Written: Secondary Care Directorate
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Responses must be received no later than 31st January 2014

I am responding: as an individual

on behalf of an organisation

<input type="checkbox"/>
<input checked="" type="checkbox"/>

(please tick a box)

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Recommendations within the draft Review of Paediatric Healthcare Services Provided in Hospitals and the Community

Although supportive of the document we have included some background, comments and points that we wish to highlight for the consultation exercise.

Background:

Primary Immunodeficiency Diseases (PIDs) are a group of over 200 rare conditions affecting the ability of the immune system to fight infection. They are life-long chronic, complex conditions that are difficult to treat and require input from different specialities. It is generally accepted that PIDs are under diagnosed and under-reported.

Reference: Clin Exp Immunol. 2014 Jan;175(1):68-78. doi: 10.1111/cei.12172. The United Kingdom Primary Immune Deficiency (UKPID) Registry: report of the first 4 years' activity 2008-2012. Edgar JD et al.,

The UKPID Registry (<http://ukpin.org.uk/home/registry-introduction.htm>) has identified Belfast as a centre with one of the largest groups of PID patients, outside of tertiary referral centres in London and Newcastle.

PID UK is a not-for-profit organisation that works to help PID affected patients and families in the UK through information, support and advice www.piduk.org. Our responses in this consultation are related to the care of these conditions however the points raised are relevant to many other rare disorders.

Q1. Does the scope of the information detailed in the review provide a comprehensive assessment of the needs for paediatric healthcare services provided in hospitals and the community over the next 10 years? YES/NO

Not fully. The issue of increasing demand on services and how capacity and services will keep pace with improved diagnoses is not addressed.
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Q2. Are the enablers for change detailed for paediatric services appropriate or do you feel there are others? YES but please see comments below
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Workforce development and training

Points 7.2 - 7.5. With over 100,000 people in Northern Ireland affected by rare disorders, including the largest cohort of patients with primary immunodeficiency outside of the two tertiary referral centres in London and Newcastle, we would like to recommend specialist training for GPs and medical staff to promote a greater awareness and understanding of rare conditions.
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Points 7.7 and 7.8. Increased numbers of advanced children's nurse practitioners would be welcomed.

PID UK would also welcome greater numbers of Immunology Clinical Nurse Specialist within hospitals for children with PIDs. Immunology CNS's are the lynchpin that helps coordinate care in the hospital and in the community and they play a vital in organizing home therapy for children with PIDs. They are seen as a vital, trusted advocate for the child and family.

Imaging and radiology – Implementation of recommendation 20 should be a high priority. It is essential that these services are available round the clock for the benefit of children.

Information Communication and Technology (ICT)

Recommendation 21

Having complete care records in one place for children through good ICT systems is very important. For children affected by rare disorders such as PIDs it will save them and their parents having to go through an explanation of their condition and will help ensure that prompt and appropriate care can be given leading to better patient outcomes in all healthcare settings.

Research - Recommendation 22

Although PID UK welcomes this recommendation further clarification is needed on how the paediatric network would work practically, on the ground. Well co-ordinated research is vitally important to drive forward new innovations for patients with complex health conditions such as PIDs and best care for patients is associated with centres that are research active.

Robust Outcomes Data - Recommendation 23

We agree good, robust data collection is essential to assess if capacity is meeting patient numbers as diagnosis of rare conditions (thankfully) improves and also to monitor outcomes of patients so as to inform best practise for improved care.

Living with chronic conditions such as PIDs can impact on quality of life so we would recommend that patient QoL outcomes and experience of service be measured as part of the package proposed.

Q.3 Are the 23 recommendations detailed in the Executive Summary of the review appropriate or do you wish to add or remove any?

YES BUT please see comments below

Recommendation 1

We are completely supportive of this recommendation. Patient experience and outcomes for children, their parents and families, can be improved by age appropriate information and active involvement in decision-making concerning care. This could be facilitated by active engagement with patient organisations.

Recommendation 2

The UKPID Registry (<http://ukpin.org.uk/home/registry-introduction.htm>) has identified Belfast as a centre with one of the largest groups of PID patients, outside of tertiary referral centres in London and Newcastle. Patients identified and cared for in Belfast have a wide range of PID conditions some of which extremely rare, but most of which are under diagnosed. They are served by the Northern Ireland Regional immunology Service on the Royal Hospitals site (<http://allergyandimmunologyNI.org/>). Rapid, early diagnoses, early intervention, treatment, care and support by self-management (where appropriate and possible through immunoglobulin therapy) are particularly important for this group of children. For families affected by PIDs there are two key areas that must work well: the relationship with their GP and 'out of hours support' through A&E when children may present with acute infection or complications. We would therefore welcome the development of formal integrated care pathways with setlines of communication to keep everyone in the loop of care. This would be helped greatly by centrally held, complete care records that could be accessed in all healthcare settings (see comments above on recommendation 21).

Recommendation 2 also refers to pharmacies forming part of the 'extended community team', as a means of managing conditions that do not require secondary care services. Given that the Health Minister has expressed a desire to reduce the number of pharmacies in NI by 100 (News Letter interview June 2011) we would hope that the pharmacy network remains accessible to everyone in all parts of Northern Ireland, especially but not exceptionally, for those people living in rural areas.

Recommendation 3

We would welcome the development of formal transition guidelines by all centres with individual plans for children and families. For children with PIDs we know this a particularly vulnerable and difficult time and needs careful, co-ordinated planning between paediatric and adult centres. Support for, and good communication with, the family is essential. How well transition works can often determine the long-term health of the patient. The plans should set out the responsibilities, timelines and communication pathways for the smooth handover into adult care. It must also be recognised that some adolescents may take longer to adjust to an adult setting so plans should be flexible and personalised.

Recommendation 4

Networks are a good idea but how these will work in practice needs to be

spelled out. As does the where, when and how patient representatives and voluntary sector are to be involved. We would welcome further clarification on this.

Recommendation 5 - We fully endorse this - age appropriate settings are important.

Recommendation 6

Children with PIDs often have acute medical needs because of their underlying inability to fight infections and delays in giving appropriate treatment can have severe consequences. Because infection and fever in children is common, the health needs of children with PIDs are often not taken seriously enough. We recommend that care providers within the proposed rapid response teams should have education about these conditions. This would include learning to listen to concerned parents who are often experts in their child's condition, know the limits of their expertise regarding the treatment and management of these rare disorders and the ability to recognise the need for swift specialist referral.

Recommendations 8 and 9

We fully support these recommendations.

Recommendation 10

'Within 4 hours' and 'within 24 hours' are long time limits for children with PIDs to wait to be assessed for appropriate care. Children with PIDs may have life-threatening infections which need prompt treatment and as stated in the document children are often less robust than adults (point 6.46). We would recommend shorter waiting times to improve patient outcomes.

Recommendation 11

Having clearly defined capacity to ensure equity of access is very important but this recommendation fails to address the need for capacity to keep pace with increased case loads as diagnostic methods for detecting rare disorders such as PIDs continues to improve.

Recommendation 12

Whilst formal partnerships within the UK and Republic of Ireland are needed we believe it is important and in patients' interests to maintain and safeguard specialist knowledge within NI. This will help limit travel for acutely ill children.

Recommendation 14

Rather than 'considered' we believe it essential that 'firm linkages' are made between all the agencies involved.

Recommendation 17

We would like to recommend that integrated care pathways need to be in place before 'step-down' occurs otherwise children with complex health needs, such as those that occur in PIDs, will be left without adequate support. The funding required for health needs in the local community should follow the patient.

Q.4 Taking account of the context and content of this document are there any other important issues not addressed? YES/NO

If NO please explain

Better liaison between healthcare providers and schools - Children with chronic rare conditions and their parents often need support at school to help them explain the condition, how any emergencies should be dealt with, how it may affect their attendance etc. A support service, professional to professional, will help relieve the strain and burden from parents who often struggle to make their voice heard in this setting and who are sometimes labelled as pushy and over-protective. Children with chronic conditions can also feel stigmatised. Providing a support service would promote an inclusion rather than exclusion policy for school activities and lead to happier, more confident children. It would also be consistent with the ethos of holistic care as recommended in the consultation document.

Please use space below to address any issues not asked in above questions.

Point 4.35

In Northern Ireland it is estimated that more than 100,000 people will be affected by a rare disease so we welcome reference to the Rare Disease Plan. For many of these conditions, including PIDs, protracted diagnosis remains a problem. We look forward to receiving detail as to how this plan will address this issue in Northern Ireland.

Equality implications

Q5. Do you think the proposals are 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

Response:

Q6. Are you aware of any evidence, qualitative or quantitative, that the proposals 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

Response:

Q7. Could the proposals better promote equality of opportunity or good relations? If yes, please give details as to how.

Yes No

Response:

THANK YOU FOR YOUR COMMENTS.

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