

Response ID ANON-EUBY-Y693-G

Submitted to **Specialised Services clinical commissioning policies and service specification - 8th Wave**
Submitted on **2016-04-15 15:37:26**

About you

1 What is your name?

Name:

Susan Walsh

2 Who are you responding on behalf of?

Who are you responding on behalf of?:

Primary Immunodeficiency UK (PID UK)

3 What is your job title?

Job title:

Director

4 What is your email address?

Email:

susan.walsh@piduk.org

Specialised Services clinical commissioning policies and service specifications

5 Would you like to comment on a service specification, or clinical commissioning policies?

Clinical commissioning policies

Clinical Commissioning Policies

12 Please indicate which clinical commissioning policy you would like to comment on:

Haematopoietic Stem Cell transplantation (HSCT) (F01X01):

Clinical Commissioning Policies (continued)

13 Has all the relevant evidence been taken into account?

No

If you selected 'No', please give details:

Supporting evidence for extending allogeneic HSCT for the primary immune deficiency chronic granulomatous disorder (CGD) to 24 years and beyond is given in:

Reduced-intensity conditioning and HLA-matched haemopoietic stem-cell transplantation in patients with chronic granulomatous disease: a prospective multicentre study.

Güngör T et al., Lancet. 2014 Feb 1;383(9915):436-48. doi: 10.1016/S0140-6736(13)62069-3. Epub 2013 Oct 23.

This study, using carefully tailored doses of the chemotherapy drug busulfan to prepare CGD patients for stem cell transplant, showed a high success and survival rate. This approach is now being extrapolated to treat other primary immunodeficiencies. Supporting data is also available through the ESID Inborn Errors Working Party that works very closely with the EBMT Inborn Errors Working Party.

14 Does the impact assessment fairly reflect the likely activity, budget and service impact?

No

If you selected 'No', please tell us what is accurate?:

The impact assessment does not include treatment of older age group of patients (>24 years). However the numbers of patients that would fall under this category would be small.

15 Does the policy proposition accurately describe the current patient pathway that patients experience?

Yes

If you selected 'No', what is different?:

16 Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that have been described?

Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that have been described?:

The rationale for a cut off point of 24 years is not clear and leaves no provision for HSCT for older people with a range of different PID conditions that are now deemed suitable for allogeneic HSCT. The policy would disadvantage this group of patients who would benefit from new conditioning regimes and HSCT protocols.

17 Are there any changes or additions you think need to made to this document, and why?

Are there any changes or additions you think need to made to this document, and why? :

To address this inequality PID UK would like to suggest inclusion of wording 'where clinically indicated HSCT for adults older than 24 years should be considered'.

This would provide equity of access to HSCT for patients of all ages ensuring funding streams keep pace with the advances in HSCT for older patients.

This would provide an all encompassing policy without the need to develop a new service development application.

18 For E03X16 only : Prescribing of Cross-sex Hormones as part of the Gender Identity Development Service for Children and Adolescents.

What are the ethical considerations, including the level of competency required to understand the implications, for a young person under the age of 16, to access cross sex hormone treatment which may result in potential harms?:

19 For B01X09 only: Proton Beam Therapy for Cancer of the Prostate.

Has the evidence review captured all the relevant and eligible papers?:

Final question

20 Before completing the survey you must declare any financial or other interests in any specialised services.

c:

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