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UKHD-HA Paper 1-01
20 November 2009
Revised to reflect changes agreed on 14/05/2010 and 10/11/10

Meetings between UK Health Departments and the Haemophilia Alliance

Background to the Establishment of these Meetings

1 These meetings are being established in line with Health Ministers' response to a specific recommendation made by Lord Archer of Sandwell in his report published on 23 February 2009

2 Lord Archer recommended the establishment of a statutory committee to advise Government on the management of haemophilia in the United Kingdom He said "This committee must be representative and its members should include specialist haemophilia clinicians, individuals from the Haemophilia Society and a representative from the Department of Health Such a group would ensure involvement by medical experts and, most importantly, it would guarantee the involvement of members of the haemophilia patient community. The committee would provide a formal, statutory structure within which patients have a voice in decisions regarding treatment and options for care We consider the formation of such a committee with its mechanism for consulting with patients, to be essential "

3. Lord Darzi summarised the Government view on 28 April 2009 "We understand Lord Archer's desire to establish a committee by statute to advise Government on the management of haemophilia in the United Kingdom Our view is that it is better to build on existing arrangements and expertise, rather than risk disrupting or duplicating those arrangements via legislation. We therefore intend to build on the existing UK-wide partnership of the Haemophilia Alliance, which consists of patients, haemophilia doctors, and others involved in their care The Alliance is jointly chaired by the Haemophilia Society and the haemophilia doctors' organisation. We will invite the Alliance to meet with Government twice yearly and the Department of Health will host and fund, these meetings This will enable the Government to receive advice from the Alliance on matters relating specifically to the care of haemophilia patients We will also ensure strong links are made between the Alliance and the independent advisory committee on the Safety of Blood Tissues and Organs (SaBTO) Representatives from the Health Departments in Scotland, Wales and Northern Ireland will be invited to participate in this new formal arrangement "

4. The remaining sections of the paper were discussed at the first meeting on 20 November 2009, to enable the group to agree its terms of reference, and how members will work together. The paper has since been modified to reflect those discussions

Purpose of the Meetings

5 To provide a mechanism by which the UK Health Departments and the Haemophilia Alliance can share information about matters relevant to the diagnosis, treatment and care of inherited bleeding disorders, and to provide a mechanism through which patients with bleeding disorders, and the NHS and social care professionals who care for them can be consulted on policy relating to treatment and care options. Similarly, the health and social care needs of families and carers of patients with inherited bleeding disorders are also included within the scope of these meetings.

Membership of the Group

6 The membership will comprise representatives from each of the four UK Departments of Health, together with representatives from the Haemophilia Alliance. The Alliance will be represented by:

- Up to eight patient representatives from the Haemophilia Society (representing England, Scotland, Wales and Northern Ireland) , and up to two officials from the Society.
- Up to seven members of the Executive of the UK Haemophilia Centre Doctors' Organisation, including one with paediatric experience, and a member from each of the four UK administrations;
- Up to four members of the Haemophilia Nurses Association.
- Up to two members of the British Association of Social Workers.
- A member of the Institute of Biomedical Sciences
- A member of the Clinical Scientists Group for Haemophilia.
- p to two members of the Chartered Association of Physiotherapists.
- A representative of specialised commissioning will be invited to attend and other experts or representatives may be invited to attend meetings on an *ad hoc* basis for certain items of business

Responsibilities of the Group

- This Group constitutes a formal route through which the Haemophilia Alliance can consult with and provide advice to the UK Health Departments.
- Where they deem it important or necessary to do so, members of the Haemophilia Alliance may consult more widely with haemophilia

patients and their carers, and with other NHS and social care professionals working in this field, before providing such advice

- The Group respects the mandates of other departmental advisory committees and panels

Terms of Reference

- To share information between the UK Health Departments and the Haemophilia Alliance and consult on all aspects of treatment and care relating to inherited bleeding disorders, including review of the National Service Specification as required.

- To ensure there is effective communication between patient representatives, health and social care professionals, and policy officials on health and social care matters of mutual interest and concern

- To ensure links are developed between this group and other groups responsible for advising Government on blood safety issues.

- In fulfilling the above, the Group recognises that health is a devolved matter, and therefore policy and practice may vary in different parts of the UK.

Meeting Arrangements and Resources

7. The Group will meet twice each calendar year in London. The meetings will be hosted and funded by the English Department of Health. A meeting note will be recorded, and provided to all members of the Group

i) Review Recommendation ...

iii) A committee to advise on all financial [illegible]
on [illegible] financial & other needs of those [illegible]
patients