

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 11AM ON WEDNESDAY 16th
JULY 2014 IN HOUSE OF LORDS COMMITTEE ROOM G, SW1A 0PW**

Present:

Baroness Wheeler – Chair

Alan Thomas – aHUS UK
Audrey Michniewicz – CF Trust
Brian Gunson – British Liver Trust
Caroline Morrice - GAIN
Catherine Harris – Communication Matters
Chris Sotirelis – UK Thalassaemia Society
Daisy Ellis – Terence Higgins Trust
Danny Beales – BLISS
Fiona Loud - British Kidney Patients Association
Georgina Grant – Gilead
John James – Sickle Cell Society
Kate Eden – Shire
Larushka Mellor – Merck Serono
Lesley Harrison – AKU Society
Luella Trickett - Baxter
Lisa O'Dea – British Society for Rheumatology
Maria Vlahakis – Macmillan Cancer Support
Morwenna Opie – PoTS UK
Nick Palmer – National Kidney Federation
Nisha Tailor – Novartis
Rebecca Gladstone – Anthony Nolan
Richard Rogerson – Niemann-Pick Disease Group
Rob Wood – The Children's Trust
Sophie Cramb – Asthma UK
Val Stevenson – Genzyme

John Murray – Secretariat
Dorothy Chen – Secretariat
Edward Nickell – Secretariat

1. APOLOGIES

A number of apologies had been received.

2. MINUTES

Agreed: the minutes of the previous meeting on Wednesday 2nd April 2014.

3. SHCA GOVERNANCE REVIEW

Reported: that a number of recommendations had emerged from the Alliance's governance review workshop, including a desire to see greater use of working groups and to strengthen lay support available to the Chair.

Considered: that the development of competition law counted in favour of an item on agendas reminding members providing goods and services of their responsibilities under the law.

Noted: that members could change the Alliance's secretariat at any time but that appointment of the secretariat would arise as a standing item each autumn. In the event of a change, the incumbent secretariat would be expected to assist in the orderly transfer of responsibilities to its successor during a notice period of not less than three months.

Agreed: the governance document and ways of working as proposed. The secretariat would set out a number of options for improving lay support to the Chair and share them with members. The following paragraph would be included on all future agendas:

“Competition law prohibits agreements between business enterprises of any kind, which have as their intention or effect a restriction or distortion of competition within the UK or the EU. Members may discuss policy developments, campaigning and advocacy activities. Members may not discuss: fixing the prices of products and services or the conditions of sale, limiting production or agree production quotas, dividing up the market or sources of supply or demand or whether or not to bid for a tender, framework or other agreement.”

4. MATTERS ARISING

4.1 New members

Reported: that The Save Babies Through Screening Foundation, the Epilepsy Society and Roald Dahl's Marvellous Children's Charity had joined the Alliance, taking its patient-related membership up to 102. Bristol-Myers Squibb had also joined as the Alliance's 14th corporate member.

4.2 NICE consultation response

Noted: the report on agenda.

5. POLICY UPDATE

5.1 NHS England leadership and structural changes

Considered: that Simon Stevens's characterisation of the Director of Specialised Commissioning as one of the most important jobs in healthcare was welcomed.

However, reports had emerged that NHS England was struggling to attract a senior figure from the provider sector to fill the role as intended. The risk was that the position would be downgraded from Board level and that further delays would be observed in NHS England's policy development processes.

5.2 NHS England policy development process

Considered: that delays around NHS England's reply could be indicative of wider confusion within the organisation in relation to the nature of its commissioning processes. Greater transparency in the development of these processes was required, not least to ensure continued improvements to patient care and access.

5.3 Derogations Report

Reported: that the Alliance had submitted a Freedom of Information (FOI) request for a copy of the derogations report on 3rd June. On 1st July, NHS England denied the Alliance's request under Section 22 of the FOI Act, which stated that public bodies are not obliged to disclose information that is intended for future publication. The Alliance requested an internal review of this decision on 10th July, arguing that it was not NHS England's intention to issue the original derogations report which was readied for publication in March. The outcome of the internal review would be communicated within 20-40 working days.

5.4 Scope of specialised services

Reported: that NHS England was in the early stages of identifying services, currently classified as specialised, which it would favour being devolved to CCGs. Noted: that, while NHS England might wish to see some services devolved to CCGs, the scope of specialised commissioning was determined by ministers through parliamentary regulation. The earliest date at which changes could be made was April 2015. NHS England had also been considering co-commissioning arrangements for specialised services between NHS England and CCGs. The meaning of co-commissioning was unclear and might range from necessary and overdue collaboration to more formal pooling of budgets.

Considered: that the Alliance should seek to inform the specialised commissioning taskforce by conducting a survey of members and clinicians about the future status of their services. While keeping the survey as simple as possible to meet time constraints, efforts should be made to define co-commissioning in a way which members could then comment on and respond to.

Agreed: that the secretariat would prepare an amended version of the survey and use it to gauge the opinions of members and relevant stakeholders in the clinical community.

5.5 Other developments

Noted: the report on agenda.

6. SPECIALISED SERVICES TASKFORCE

Reported: that the secretariat had prepared a draft submission to the specialised commissioning taskforce. The document was intended to represent members'

collective position on some of the recommendations which were likely to emerge from the taskforce work and to provide a basis for future engagement.

Noted: that Jane Ellison stated in a Parliamentary Answer dated 7th July that there had been no plans to consult on the outcomes of the taskforce work, despite NHS England's initial promise for a programme of engagement. Subsequent communication with NHS England officials revealed that, while no formal consultation was planned for the taskforce recommendations, engagement would take place on specific issues through relevant channels and via topic-specific workshops.

Considered: that, in the absence of clear and structured external engagement, members were left with no option but to write to the taskforce directly. The Alliance's submission would need to be shared with the taskforce as soon as possible to achieve its desired impact.

Agreed: that the secretariat would recirculate the draft submission to members for comment and approval prior to sharing it with the taskforce.

7. PARLIAMENTARY EVENT AND FUTURE ENGAGEMENT

Reported: that the event had proved successful with good levels of attendance and engagement, helping to raise the profile of the Alliance and its manifesto at an important time.

Noted: the view that the greatest value had derived from the parliamentary lobby rather than the reception. There was a desire to maintain momentum ahead of the 2015 General Election.

Agreed: that the secretariat would develop the Alliance's engagement plan for next year and share it with members for comment.

8. NHS ENGLAND GENERIC POLICIES

Considered: that the Alliance had been firm in calling for a structured engagement on the generic policies, whereby the ethical framework would be updated and consulted on first to establish the relevant groundwork for other generic policies. The risk was that NHS England's piecemeal approach would give rise to inconsistency across different aspects of the generic policies, which might have a knock-on effect for the management of Individual Funding Requests (IFR) and the process of in-year service developments.

9. SCOTLAND EVENT

Considered: that, regardless of the outcome of the Scottish Independence Referendum, there was value in bringing together key stakeholders to discuss policy priorities within NHS Scotland for people with rare and complex conditions. The event would also be a good opportunity to highlight the Scottish Implementation Plan for Rare Diseases and ensure that the Plan was properly resourced.

Agreed: that the secretariat would prepare a written proposal for the Scotland event and share it with members for comment and approval.

10. UK STRATEGY FOR RARE DISEASES

Noted: as reported on agenda.

11. LUNCH GUEST

Reported: that Professor David Walker, Deputy Chief Medical Officer for England, would be the Alliance's lunch guest. A note of the lunch discussion is attached as an appendix.

Noted: that Sir Ian Gilmore, Chair of the Prescribed Specialised Services Advisory Group, would be the Alliance's next lunch guest.

12. REPORT ITEMS

Report items were taken as per the notes on agenda.

12.1 Patient and Public Voice Assurance Group

12.2 Health + Care Commissioning Event 2014

12.3 HSJ Article

12.4 Westminster Health Forum

12.5 GAUK patients' charter

13. DATES OF NEXT MEETINGS

Reported: that the Alliance's final quarterly meeting of 2014 would be held on Wednesday 15th October from 10am until 1pm in Central London. Members would be notified of a venue closer to the date.

14. ANY OTHER BUSINESS

Agreed: that the secretariat would approach Dr Sarah Wollaston, the new Chair of the House of Commons Health Select Committee, for a meeting to discuss the Alliance's overarching priorities and other issues around specialised commissioning.

The Chair closed the meeting at 12.30pm.

Appendix: Note of lunch discussion with Professor David Walker, Deputy Chief Medical Officer for England

Professor David Walker, Deputy Chief Medical Officer for England, joined members over lunch to discuss his responsibilities in relation to rare diseases and NHS England's role in commissioning related services.

Professor Walker began by noting key elements of the UK Strategy for Rare Diseases, which included: ensuring care and research coordination, enabling early diagnosis, supporting effective commissioning processes and improving patient and public engagement. The aim of the strategy, he explained, was to secure high quality care for people with rare diseases similar to that for people with more common conditions.

Part of Professor Walker's role as the rare diseases lead for England was to ensure that the Strategy retained a sufficiently high profile within the Department of Health. He was also involved in ensuring successful implementation of the Strategy through the UK Rare Diseases Forum and via ongoing liaison with counterparts in the devolved nations. He emphasised that input from rare diseases stakeholders was central in all aspects of this work.

On specialised commissioning, Professor Walker recently met with Dr Paul Watson to discuss his work leading NHS England's specialised commissioning taskforce. Professor Walker supported the Alliance's call for the new Director of Specialised Commissioning to have board-level responsibility, and expressed concern around the length of time it might take to secure a new Director and the potential delays this might cause in relation to rare diseases.

Turning to questions, members enquired how decisions would be made to change the future scope of specialised services. Professor Walker explained that this was a matter for ministers to decide with recommendations from NHS England and the Prescribed Specialised Services Advisory Group (PSSAG). The Department of Health had been firm in calling for an early dialogue with NHS England on this matter so that it could be sighted on proposals before they were made public.

Members also highlighted the lack of transparent processes for submitting new services for consideration by PSSAG for direct commissioning by NHS England, as well as for submitting service development proposals to Clinical Reference Groups (CRGs). Professor Walker agreed to investigate this matter on members' behalf, but suspected that much of the issues around policy development were the result of poor capacity within NHS England's specialised commissioning team.

Professor Walker also agreed to investigate a number of other issues on members' behalf, including the extent of potential co-commissioning arrangements for specialised services and the progress made towards NHS England's Pathfinder programmes.

Professor Walker welcomed the opportunity for a continuing dialogue with members and agreed to answer any further questions by email:

david.walker@dh.gsi.gov.uk