

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 11.00AM – 2.00PM ON
WEDNESDAY 13th JULY 2016 AT ARCHBISHOP'S ROOM, MILLBANK HOUSE,
WESTMINSTER**

Present:

Baroness Wheeler – Chair*
Lord Sharkey – Vice-Chair*
Baroness Redfern – Vice-Chair*

Andy Barrick – MSA Trust
Brian Gunson – British Liver Trust
Catherine Harris – Communication Matters
Chris Sotirelis – UK Thalassaemia Society
Ciaran Scott – AKU Society
Daisy Doncaster – MS Trust
Darren O'Keefe – CF Trust
Debbie Flanagan – Gilead Sciences
Dominic Wake – Novartis
Finn O'Dwyer – Epilepsy Society
Fiona Loud – British Kidney Patient Association
Gary Jones – AbbVie
Gemma Gapper – Shire
Ipek Gunduz – Baxter
Jeff Courtney – Haemophilia Society
Jeremy Felvus – Pfizer
John Kell – MND Association
Joseph Clift – Asthma UK
Laura Szutowicz – HAE UK
Lynne Regent – Anaphylaxis Campaign
Marta Salamonowicz – Children's Heart Federation
Meriel Miller – The Children's Trust
Miguel Souto – British Society for Rheumatology
Morwenna Opie – POTS UK
Richard Rogerson – Niemann Pick Disease Group
Sarah Radcliffe – National AIDS Trust
Simon Butler – Anthony Nolan

John Murray – SHCA
Andrew Wilkinson – SHCA

* for part of the meeting only

1 COMPETITION LAW COMPLIANCE

Members noted their obligations under competition and bribery law.

2 APOLOGIES

Reported: that a number of apologies had been received.

3 MINUTES

Agreed: the minutes of the last meeting on Wednesday 13th April 2016, which would now be published on the Alliance's website.

4 MATTERS ARISING

4.1 Membership and corporate supporter changes

Reported: that the LPLD Alliance had joined the SHCA, taking patient-related membership up to 120. Sanofi Genzyme had left the Alliance, with Amgen joining as a corporate supporter.

4.2 New Vice-Chair

Reported: as per the notes on agenda.

Noted: that Baroness Redfern's appointment would mean that the Alliance would have office-holders from each of the main political parties in the House of Lords.

Agreed: that Baroness Redfern would become a Vice Chair of the Alliance.

5 POLICY UPDATE

5.1 Personnel changes

Reported: as per the notes on agenda.

5.2 Brexit

Reported: that the implications of Brexit on rare diseases and the associated specialised services could be far-reaching.

Considered: that the Alliance might usefully prepare a paper surveying the areas potentially affected by withdrawal from the European Union with relevance for specialised healthcare, both as a resource for members' use and as a means of determining whether the Alliance should engage with policymakers directly on these issues.

Noted: that members might themselves have useful information to contribute to such a paper. A range of think-tanks and other institutions were producing material on the impact of Brexit on the wider NHS.

Agreed: that the secretariat would prepare a draft paper on the implications of Brexit for specialised healthcare for member consideration and additions. Members could then determine whether or not the Alliance should engage with Brexit-related issues.

5.3 NHS finances

Reported: as per the notes on agenda.

Considered: that a re-set of NHS finances was expected, with Department of Health accounts due to be presented to parliament in the near future.

5.4 CRG consultation response

Reported: that NHS England had finalised its Clinical Reference Group reforms and had been in the process of recruiting clinical and patient members to the new bodies. A number of CRGs had not been able to appoint the full complement of patient and public voice representative members to date.

Considered: that, while several organisations were unhappy with some of NHS England's decisions relating to individual CRG closures or mergers, members had broadly welcomed the care with which NHS England's consultation response set out its rationale for each decision. Nevertheless, during the course of the consultation a number of members had sought to meet or write to NHS England but had not received responses.

Noted: that the poor level of patient and public voice registration possibly related to the burdensome application process, about which many members had registered complaints with NHS England directly.

Agreed: that the Alliance would write again to NHS England to communicate concerns on the CRG application process for prospective patient and public voice members and seek to chart a way forward.

6. NAO REPORT ON SPECIALISED COMMISSIONING

6.1 NAO Report

Reported: as per the notes on agenda.

6.2 Public Accounts Committee hearing

Reported: as per the notes on agenda.

Considered: that the Public Accounts Committee's final report was due for publication imminently. The Alliance had written to the Committee's Chair to provide further input following NHS England's evidence session in June.

Noted: that concerns that discussion of medicines costs would crowd out the other findings of the NAO's report.

7. SPECIALISED SERVICES COMMISSION REPORT

Reported: that the Commission had completed its report, which was published at the end of April 2016.

Considered: that supporting the Commission was a major component of the Alliance's 2016 work programme. It had worked to tight timescales given NHS England's concurrent development of its strategic framework, and this had increased the importance of close links between the Commission and NHS England during the months in which the former's recommendations and the latter's report were being developed. NHS England's strategic framework reflected many of the Commission's recommendations, often very closely. However, in omitting other, associated, recommendations NHS England risked losing vital elements of the Commission's overall vision of the future. Alliance members had found the Commission's report helpful and included links to the document on their own websites.

Agreed: that the Commission's recommendations should inform the Alliance's policy work in the second half of the year.

8. SPECIALISED SERVICES STRATEGIC FRAMEWORK

Reported: that NHS England's strategic framework had been described as a 'fundamentally new direction for specialised services'. A presentation was given outlining the key elements of the framework and their level of alignment with the Alliance's established policy positions and the recommendations of the Specialised Services Commission.

Considered: that the strategic framework erased system boundaries across specialised services, with new relationships proposed between providers and commissioners, as well as national and local budgets. To the extent that these flexible arrangements were underpinned by clear-cut national accountability for specialised services and clear, meaningful national service specifications, the strategic framework aligned with members' priorities. However, there were concerns about the provisions relating to 'pooled budgets' and service

specifications focusing on 'outcomes' with an eye on viability 'within resource envelopes'. While recognising that some service specifications would benefit from revision, it was considered best to conduct this on a case-by-case basis, rather than wholesale changes as implied by the framework. Members also felt that greater clarity on the role and remit of Sustainability and Transformation Plan areas in relation to the strategy would be helpful. For the purposes of informing the development of the supporting detail for the strategic framework, the Alliance might usefully seek to press NHS England to reflect the Commission's recommendations more comprehensively, including those relating to national specifications and accountability.

Agreed: that the secretariat would circulate the presentation delivered to members. The Alliance would engage with NHS England to inform the development of the strategy for specialised services and, in doing so, would pick up on the Commission's recommendations.

9. PRIORITISATION METHODS

Reported: that further to the notes on agenda, NHS England had now published 'provisional' investment decisions for specialised services in 2016/17. These related to 18 proposals recommended for investment out of 22 considered. A further 44 'in-year service developments' had been considered, of which 12 were recommended for funding. The 'provisional' decisions pended legal challenge on whether NHS England was responsible for commissioning HIV prevention therapies, which NHS England stated would require the prioritisation process to be re-run if so.

Considered: that the process remained far from predictable and transparent, as desired by the Alliance and other stakeholders. The categorisation of so many proposals as 'in-year service developments' and its definition were also difficult to understand. The Alliance had been concerned at how highly specialised service proposals might fare in relative prioritisation against more common conditions and these fears appeared to have been borne out.

Noted: that Noel Gordon had replied to a letter from the Alliance's Vice Chair, Lord Sharkey, recognising concerns about rare disease prioritisation but had not given concrete assurances on the associated issues. While it was welcome that NHS England had published the ranking of each proposal, members continued to be frustrated by the absence of clear published rationales for each decision made. This was particularly frustrating for proposals which related to treatments previously routinely commissioned or which had been thought to have a high likelihood of being prioritised for investment. More broadly, members were uncomfortable with NHS England's decision to publish 'provisional' decisions pending legal rulings, with the accompanying commentary from NHS England appearing to set one group of patients against others requiring new treatments.

Agreed: that the Vice Chair would reply to Noel Gordon's letter to reiterate the

Alliance's concerns on rare disease prioritisation and the need for greater transparency in the prioritisation process. The secretariat would monitor further developments on prioritisation decisions and update members.

10. NHS ENGLAND REGIONAL MEETINGS UPDATE

Reported: as per the notes on agenda.

Considered: that NHS England's intention to revisit collaborative commissioning was a particular concern if pooled budgets were being considered. The Alliance had sent comments on a collaborative commissioning engagement paper to the Patient and Public Voice Assurance Group.

Agreed: that the secretariat would continue to engage with NHS England on collaborative commissioning and would seek permission to circulate the collaborative commissioning engagement paper to members.

11. RARE DISEASES

11.1 Impact of Brexit

Reported: as per the notes on agenda.

11.2 UK Rare Disease Forum

Reported: as per the notes on agenda.

Considered: that the moves to diminish patient membership of the Forum's successor policy group were retrograde and unwelcome. The Chair had written to the Minister for Life Sciences in relation to these measures.

Agreed: that the secretariat would circulate the Minister's reply to the Chair when available.

12. DEVOLVED NATIONS

Reported: that further to the notes on agenda, members would need to determine the extent of the Alliance's activity in the devolved nations for the remainder of the year.

Considered: that members would find engagement with the devolved nations worthwhile, and in particular meeting with the new Director of the National Services Division in Scotland and the new commissioning team at NHS Wales.

Agreed: that the secretariat would seek to arrange meetings or calls with Scotland and Wales in the second half of the year.

13. LUNCH GUEST

Reported: that Dr Jonathan Fielden, NHS England Director of Specialised Services Commissioning and Deputy National Medical Director, would be the Alliance's lunch guest.

Agreed: to split the discussion with Dr Fielden between consideration of the new strategic framework for specialised services and discussion of the prioritisation process and related decisions.

14. REPORT ITEMS

Reported: as per the notes on agenda.

14.1 Accelerated Access Review/Office for Life Sciences innovation guide

14.2 *Health Service Journal* opinion piece

14.3 George Freeman event

14.4 Meetings with ABPI

14.5 Meetings with Noel Gordon and Jonathan Fielden

14.6 National Voices AGM

15. DATES OF NEXT MEETINGS

Reported: that the Alliance's final quarterly meeting for 2016 would be held in central London on Wednesday 12th October from 11am to 2pm (inclusive of the lunchtime guest speaker discussion).

16. ANY OTHER BUSINESS