

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 10.00AM – 1.00PM ON
WEDNESDAY 13th APRIL 2016 AT 21 ARLINGTON STREET, GREEN PARK, LONDON,
SW1A 1RN**

Present:

Baroness Wheeler – Chair
Lord Sharkey – Vice-Chair

Alex Massey – Neurological Alliance
Alex Phillips – Terence Higgins Trust
Anna Lewis – British Society for Rheumatology
Brian Gunson – British Liver Trust
Caroline Morrice – GAIN
Caroline Brocklehurst – Teenage Cancer Trust
Catherine Hodder – Young Epilepsy
Ciaran Scott – AKU Society
Daisy Doncaster – MS Trust
Dan Rattigan – MS Society
Finn O'Dwyer – Epilepsy Society
Fiona Loud – British Kidney Patient Association
Georgina Grant – Gilead Sciences
Ipek Gunduz – Baxter
Jane Darragh – CLIC Sargent
Jeff Harper – The Children's Trust
Jerome Penn – Pfizer
Joe Brice - Baxalta
Joseph Cliff – Asthma UK
Lynne Regent – Anaphylaxis Campaign
Nisha Tailor – Novartis
Patricia Osborne – Brittle Bone Society
Richard Rogerson – Niemann Pick UK
Rosanna Preston – CLAPA
Sarah Radcliffe – National AIDS Trust
Sarah Love-Jones – British Pain Society
Simon Butler – Anthony Nolan
Steve Bojakowski – Sobi

Andrew Wilkinson – SHCA
John Murray – SHCA
Mark Loughridge - SHCA

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 January 2016, which would now be published on the Alliance's website.

4 MATTERS ARISING

4.1 Membership changes

Reported: that HAE UK had joined the Alliance, taking patient-related membership to 119. Bayer had left the Alliance, but Amgen had since joined, keeping corporate supporter numbers at 16.

4.2 New Vice-Chair

Reported: as per notes on agenda.

Noted: that the Alliance continued to seek a Vice Chair from the Conservative Party to demonstrate cross-party support.

Agreed: Lord Sharkey's appointment as Vice-Chair of the Alliance.

4.3 Status of companies within the Alliance

Reported: as per notes on agenda

Considered: that it would be sensible for the Alliance to distinguish between patient members and corporate supporters so that compliance with industry guidelines was clear for all to see. Corporate supporters would be able to attend meetings and participate in discussions, but the Alliance's policy positions would be determined by its patient-related members exclusively.

Noted: that other organisations of a similar constitution to the Alliance had comparable measures in place.

Agreed: that companies within the Alliance should become corporate supporters, distinct from patient-related members, as proposed. The secretariat would prepare an amendment to the Alliance's governance documents and share this with members for agreement by written procedure. Subject to final agreement, the amended governance documents would then be published online.

5 POLICY UPDATE

5.1 Personnel changes

Reported: As per the notes on agenda

Noted: that it was not yet known whether there would be further changes to the structure of the specialised commissioning directorate under Jonathan Fielden's leadership.

5.2 NHS finances

Reported: as per the notes on agenda.

Considered: what role specialised services might play within the 44 Sustainability and Transformation Plan (STP) footprints being established across the country, which were seeking to solve long-standing financial problems within health economies, along with wider issues of care quality and population health. The Alliance should remain alert to how specialised services might fit within these arrangements and engage if necessary.

Agreed: that the Alliance would monitor developments with STPs and seek to discuss these with the relevant lead at NHS England if possible.

5.3 NHS England business plan

Reported: that, as per the notes on agenda, NHS England's 2016/17 business plan envisaged collaborative commissioning underpinned by national service specifications for specialised care.

Considered: that the Alliance was supportive of the current collaborative commissioning arrangements, in contrast to previous plans to introduce 'co-commissioning' with pooled national and local budgets, which had caused concern.

Noted: that collaborative commissioning arrangements were likely to be at their most advanced within Greater Manchester, where national service specifications would nevertheless remain in place.

Agreed: to keep the further development of collaborative commissioning under close review.

5.4 NHS England conflict of interests policy

Reported: as per notes on agenda.

Noted: that NHS England's conflicts of interest paper had been long-awaited following proposals to reform the Patient and Public Voice Assurance Group which had been raised in November 2015.

Considered: that individually and collectively, Alliance members abided by strict codes of conduct and declared conflicts of interest as a matter of course.

Agreed: that partnership working was essential to informed commissioning and necessarily involved active management of interests to avoid conflicts arising.

5.5 National Tariff

Reported: as per the notes on agenda.

Considered: that while it was welcome that a marginal rate for specialised services would not be introduced in 2016/17, members noted that it remained possible that this would be brought back in for 2017/18. Moreover, the Alliance noted the significant impact which the CQUIN announcements would have on provider finances separately to the payment system, and noted the strains on specialised provider finances and the continued debate between commissioners and providers on this score.

5.6 Cancer Drugs Fund reforms

Reported: as per notes on agenda.

5.7 Generic policies

Reported: as per notes on agenda.

Considered: that the current pace of development for generic policies was highly unsatisfactory and that NHS England needed to follow through on its commitment to hold an adequate consultation on the matter. It was possible that NHS England would distinguish between the more contentious generic policies, including those for Individual Funding Requests, in-year service developments and clinically critically urgent cases, and the other policies which were closer to an expression of statutory obligations. Consultation on the latter might take place sooner than the former.

Agreed: that the Alliance should keep up the pressure on NHS England for a proper review of the IFR and policies, which had first been promised in March 2013 for completion by October of the same year.

6. POLICY DEVELOPMENT PROCESS

Reported: that NHS England had opened a consultation on the process and methods to be used by CPAG to compare and prioritise competing proposals for new investments in specialised services.

Considered: that the Alliance would be responding to the consultation on CPAG's processes and methods, with particular reference for the need for transparency of decisions and their rationale which was absent from the consultation document. The Alliance should also seek further assurances on how rarity would be taken into account by CPAG. M

Noted: concern at the suggestion that NICE would not be consulting the public before publishing its methodology for supporting NHS England's policy development process for 2017/18.

Agreed: that the secretariat would pursue these matters and prepare a draft response to the consultation and share this with members for comment within a fortnight.

7. SPECIALISED SERVICES COMMISSION

Reported: that, in addition to the notes on agenda, the drafting of the report was nearing completion and was due to be circulated to Commission members shortly.

Considered: that the report's final form and recommendations would be for Commission members to decide but there had been strong support for national service specifications to date, as well as an emphasis on greater provider leadership and networking in future.

8. CLINICAL REFERENCE GROUP PROPOSALS

Reported: as per notes on agenda.

Considered: that, in reforming the CRGs, NHS England should ensure that their members are equipped with good quality information on outcomes, finances and the policy context in order to develop better recommendations. Notwithstanding concerns on specific CRG mergers, members broadly welcomed the shift towards greater professionalism in the operation of CRGs as a whole.

Noted: the importance of NHS England demonstrating that consultation had been meaningful and that well-founded concerns had been acted upon.

9. DEVOLUTION

Reported: as per notes on agenda.

Considered: that Jon Rouse's appointment as Chief Officer of Greater Manchester Devolution was welcome. The Alliance had recently engaged with Jon during the passage of the Devolution Act.

Noted: that the arrangements for specialised services in Greater Manchester now followed a 'delegation' model, with national service standards still mandatory and NHS England remaining ultimately accountable. In order to provide greater understanding of relevant developments taking place in Greater Manchester, members discussed the possibility of an expert speaker being invited to join members as a future Alliance lunch guest.

Agreed: that the secretariat would seek to invite a Greater Manchester representative to attend a future quarterly or specially-arranged meeting.

10. NAO STUDY

Reported: as per the notes on agenda.

Considered: that the NAO's study would be focusing on the past implementation of specialised commissioning arrangements less than the future direction of policy. This examination would likely be rooted in empirical evidence, thus allowing for a rigorous examination of NHS England's processes and decision making. The Alliance would want to publicise the report with commentary if possible. A Public Accounts Committee hearing on the report would also be held and the Alliance would seek to provide briefing.

11. MEETINGS WITH COLLABORATIVE COMMISSIONING HUBS

Reported: that in 2013 the Alliance had held valuable discussions with NHS England's Area Teams. Three years on and with Area Teams' successor 'collaborative commissioning hubs' playing an expanded role in specialised commissioning, the Alliance had agreed to repeat the meeting programme and discuss the challenges and opportunities facing the hubs across England.

Considered: that the value of the programme would be enhanced through the participation of members, especially those with a regional presence. The secretariat was also preparing a discussion guide for the meeting programme which would be circulated to members as a whole for input.

Agreed: that the secretariat would circulate a discussion guide ahead of the meeting programme for members' comments and would seek to facilitate member attendance at the meetings where possible.

12. LUNCH GUEST

Reported: as per notes on agenda.

13. REPORT ITEMS

13.4 Call with Welsh Health Specialised Services Committee

Reported: that, further to the notes on agenda, the Alliance would continue to keep in touch with developments in Wales after the upcoming Assembly elections.

13.7 UK Rare Disease Forum

Reported: as per the notes on agenda.

Considered: that the Alliance had registered concerns that the Forum's report had not been published on the Department of Health's website, which might be seen as a lack of commitment from the Department to the issue. The Forum's next report to ministers would be due in two years' time.

Reported as per notes on agenda:

13.1 Accelerated Access Review

13.2 Internal Medicine National Programme of Care webinar

13.3 Meetings with Noel Gordon

13.5 Meeting with Julie Wood, Chief Executive of NHS Clinical Commissioners

13.6 Genetic Disorders UK conference

13.8 Meetings during January to April

14. DATES OF NEXT MEETINGS

Reported: that the Alliance's next meetings were to be held on:

Wednesday 13th July

Wednesday 12th October

These would be held from 11am to 2pm, inclusive of the lunchtime guest speaker discussion, in central London.

15. ANY OTHER BUSINESS

No further business was tabled.