

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 11.00AM – 2.00PM ON
WEDNESDAY 13th JANUARY 2016 AT THE EDUCATION ROOM, ONE BIRDCAGE WALK,
WESTMINSTER, SW1H 9JJ**

Present:

Baroness Wheeler – Chair

Aaron Revel – Action Duchenne
Alex Massey – Neurological Alliance
Alex Phillips – Terence Higgins Trust
Andy Barrick – MSA Trust
Anna Lewis – British Society for Rheumatology
Anne Keatley-Clarke – Children's Heart Federation
Bimpe Joseph – Actelion
Brian Gunson – British Liver Trust
Caroline Brocklehurst – Teenage Cancer Trust
Caroline Morrice – GAIN
Catherine Harris – Communication Matters
Daisy Doncaster – MS Trust
Dan Rattigan – MS Society
Debra Morgan – Pfizer
Diane Splevings – Shire
Glenn Darley – Sobi
Henry Featherstone – Genzyme/Sanofi
Ipek Gunduz – Baxter
Jim Higgins – National Kidney Federation
John Kell – MND Association
Joseph Clift – Asthma UK
Josie Anderson – Bliss
Liz Carroll – The Haemophilia Society
Maria Piggitt – PNH Support
Nicholas Palmer – BKPA
Rebecca Griffiths – UKPIPS
Richard Rogerson – Niemann Pick Disease Group
Scott Purdon – Gilead Sciences
Shannah Adams – Marfan Trust
Simon Butler – Anthony Nolan
Sonia Malik – CLIC Sargent
Sue Farrington – Scleroderma and Raynaud's UK

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 14th October 2015, which would now be published on the Alliance's website.

4 MATTERS ARISING

4.1 New members

Reported: that PNH Support and the Pituitary Foundation had joined the Alliance, taking the number of patient-related organisations in membership up to 118.

5 POLICY UPDATE

5.1 NHS England personnel

Reported: that, further to the notes on agenda, the Director would be holding an initial meeting with Jonathan Fielden on Friday 29th January 2016 to introduce the Alliance, and that Jonathan had also agreed to join members at the Alliance's July quarterly meeting.

Considered: that members were pleased to have the opportunity to meet Jonathan Fielden in July and that, although an earlier meeting date could be requested, a July meeting would deliver most value, with Jonathan having been fully in post for a few months.

Agreed: that the secretariat would report back to members on the initial meeting with Jonathan Fielden and would also confirm the July meeting date with his office.

5.2 NHS finances and future projections

Reported: as per the notes on agenda.

Noted: that while the budget growth allocated to specialised commissioning was greater than the increases seen in other parts of the health service, it remained at the lowest end of future cost assumptions. There were clear indications that NHS England would be looking for efficiency savings in specialised services throughout the course of the current parliament.

5.3 Mapping specialised funding allocations locally

Reported: as per the notes on agenda.

Noted: that commissioning responsibilities were unchanged by this mapping

exercise, which was intended to develop a better understanding of total commissioning spend per area.

Considered: that the final specialised service spending quantum per CCG area was not broken down by specific disease area, which limited the utility of the information. There were further concerns on the validity of the data, given that NHS England had noted that accurate costings were only available for half of specialised services. The development of 'notional' allocations was in line with the Alliance's recent campaign on retaining national commissioning while encouraging collaboration between national and local commissioners.

Agreed: that the secretariat would circulate a link to the modelling data to members.

5.4 National tariff

Reported: that, following the Comprehensive Spending Review, NHS Improvement had confirmed that the 2016/17 National Tariff would not include a marginal rate for specialised services, as had previously been expected.

Noted: that the Alliance had raised concerns on the potential impact of this measure on patient access to specialised care, and the change of policy was therefore welcome.

Considered: that while providers' financial settlement for 2016/17 was likely to be improved, those providers currently under the Default Tariff Option (having declined a marginal rate for specialised services in 2015/16) would continue to be unable to access CQUIN payments for the rest of the current financial year. The importance of payment systems for specialised services, potentially including multi-year settlements, was under consideration by the Specialised Services Commission. Anita Charlesworth (Chief Economist at the Health Foundation and Chair of the Specialised and Complex Care Advisory Group) had agreed to provide a paper on the subject to the Commission.

5.5 Government's Mandate to NHS England

Reported: as per the notes on agenda.

6. SPECIALISED CARE DEVOLUTION

6.1 Cities and Local Government Devolution Bill

Reported: that the legislation was nearing the end of its passage through parliament, with the Lords now debating amendments made in the Commons. Notably, in recent remarks to the House of Lords, the Minister Lord Prior had again reiterated that any future devolution within the NHS would not affect lines of accountability. This would mean that NHS England retained its overall accountability for specialised services.

Noted: that the Alliance had rapidly undertaken a series of important meetings in relation to the devolution legislation to communicate members' concerns about the legislation as originally drafted. These were thought to have been helpful in

securing greater protection for specialised services in future.

Considered: that a high bar had been set by NHS England for future devolution arrangements to be approved and, as a result, substantial further devolution was not presently expected.

Agreed: that the impact of devolution on day-to-day accountability would nevertheless need to be kept under close review.

6.2 DevoManc

Reported: that planning remained underway in relation to the devolution of specialised commissioning responsibilities to Greater Manchester. In particular, the extent to which Greater Manchester would be financially autonomous and able to chart its own course for specialised services was not yet clear. In any circumstances, Greater Manchester system leaders had been clear that they would meet or exceed national service specifications for specialised care.

Noted: that Sir Howard Bernstein (Chief Executive, Manchester City Council) had also indicated that his ambitions for healthcare in Greater Manchester could be achieved within current legal structures.

Considered: that Greater Manchester had been considering the stratification of specialised services into different commissioning tiers, as per the report previously circulated to SHCA members. It was not yet clear how this work related to similar planning within Clinical Reference Groups and NHS England nationally. Furthermore, while devolution would 'go live' in April 2016 as envisaged by the Memorandum of Understanding, it was not clear what form this would take and whether 2016/17 might more accurately be seen as a transitional year.

Agreed: that it was important for the Alliance to continue its engagement with Greater Manchester leaders in the months and years ahead.

7. SPECIALISED SERVICES COMMISSION

Reported: that several prominent organisations had expressed an interest in responding to the Specialised Services Commission's recent call for evidence.

Noted: that because the Alliance would not be submitting a collective response to the Commission, it was important for members to respond to the call for evidence direct, as this would help guide discussions and shape the Commission's final output.

Considered: that NHS England had been engaged with the Commission's work from the outset and were represented on the Commission as observers. Jonathan Fielden was already aware of the Commission and its scope. Additionally, around one third of members present indicated that they would be looking to respond to the Commission's call for evidence.

8. PATIENT AND PUBLIC VOICE ASSURANCE GROUP

Reported: as per the notes on agenda.

Noted: that many organisations, including the Richmond Group of charities, had strongly criticised NHS England's recent proposal to prevent organisations in receipt of industry funding from sitting on NHS England groups. The Alliance's governance had been reviewed in early 2014 but this did not preclude further changes eg in the status of corporate members in case of need.

Considered: that patient organisations and others often had a spectrum of donors and sponsors without prejudice to their independence, and that the contribution of these groups, as well as the Alliance, to forums such as the PPVAG were important to patients. While the PPVAG's work programme now tended to focus on assuring consultation processes rather than broader issues within specialised commissioning, Alliance members saw continued membership as important. In particular, the Alliance was scrupulous in avoiding therapy-specific issues while its reluctant decision to publish PPVAG minutes in the interests of transparency should not be linked to membership.

Agreed: that members wished the Alliance to remain a member of the PPVAG. The primary objective in discussions with Jonathan Fielden should be optimal relations with NHS England.

9. NATIONAL AUDIT OFFICE

Reported: as per the notes on agenda.

Noted: that members had provided valuable case studies for the NAO to consider including in its report and that the Deputy Director had held a number of meetings with the NAO team to discuss and inform its findings. A further meeting would be held in February prior to the report's finalisation.

Considered: that the NAO's review appeared to be fairly comprehensive and publication of the report would most likely take place at the end of April or early May 2016.

Agreed: that the Alliance might wish to consider the ways in which it could raise awareness of the report when published and to feed into the Public Accounts Committee's consideration of it, as appropriate.

10. UK RARE DISEASE FORUM

Reported: as per the notes on agenda.

Noted: that some of the commitments that had accompanied the UK Rare Disease Strategy's launch remained unfulfilled, and that these should be raised at future meetings of the UK Rare Disease Forum.

Considered: that the Forum's report to Ministers contained challenges as well as coverage of successes in the implementation of the UK Strategy. Members wishing to provide further input on progress and challenges relating to the UK Strategy for Rare Diseases should contact the secretariat, who would be able to

convey these at future Forum meetings, as well as in the Scottish Rare Disease Implementation Oversight Group.

11. LUNCH GUEST

Reported: as per the notes on agenda.

12. MEETINGS WITH COLLABORATIVE COMMISSIONING HUBS

Reported: that the Alliance would be seeking to meet NHS England's collaborative commissioning hubs as part of its work programme for the year and that members were invited to join meetings across the country.

Considered: that meetings were likely to be scheduled in the Spring. Members interested in joining these meetings should notify the secretariat, including the regions where they would be able to join meetings.

Agreed: that members would advise the secretariat of their ability to attend meetings with collaborative commissioning hubs across the country.

13. REPORT ITEMS

Reported: as per notes on agenda.

13.1 Accelerated Access Review

Considered: that the Alliance had been asked to convene a roundtable to contribute members' views directly to the AAR team but this had been cancelled at short notice by the Review team given capacity constraints. Instead, the secretariat would seek to attend an engagement event to feed in members' views during January.

13.2 Letter to Chief Secretary of the Treasury

13.3 Specialised and Complex Care Advisory Group

13.4 Rare Disease Advisory Group

13.5 NHS England Policy Development Process

13.6 Westminster Hall Debate on Innovative Medicines

13.7 Meetings with Noel Gordon and Richard Jeavons

13.8 Cancer Drugs Fund Consultation

13.9 Meetings during October to January

13 DATES OF NEXT MEETINGS

Agreed: that the Alliance's meetings for 2016 would be held on:

Wednesday 13th April

Wednesday 13th July

Wednesday 12th October

All meetings would be held from 11am until 2pm, inclusive of the lunchtime guest speaker discussion, in central London. Further details would be announced in due course.

14 ANY OTHER BUSINESS

No other business was tabled.