

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 10AM ON WEDNESDAY 15th
OCTOBER 2014 IN 21 ARLINGTON STREET, LONDON, SW1A 1RD**

Present:

Baroness Wheeler – Chair

Alex Massey – Neurological Alliance
Andrew Baranowski – British Pain Society
Anne Keatley-Clarke - Children's Heart Federation
Audrey Michniewicz - CF Trust
Bimpe Joseph – Actelion
Brian Gunson – British Liver Trust
Camilla Horwood – NovoNordisk
Caroline Morrice – GAIN
Chris Sotirelis – UK Thalassaemia Society
Danny Beales – Bliss
David Ryner – CML Support Group
Debra Morgan – Pfizer
Diane Splevings - Shire
Fiona Loud – British Kidney Patients Association
Gill Yaz - Shine
Janet Mills – Save Babies Through Screening Foundation UK
John Kell – Motor Neurone Disease Association
Kerry Leeson-Beevers – Alstrom Syndrome UK
Larushka Mellor – MerckSerono
Laura Courtney – CLIC Sargent
Liz Carroll – Haemophilia Society
Lucinda Roberts – British Lung Foundation
Maria Vlahakis – Macmillan Cancer Support
Matthew Buckland – UKPIN
Morwenna Opie-Moran – PoTS UK
Nicola Ritchie – Baxter
Nicolas Palmer – National Kidney Federation
Nigel Nicholls – BioMarin
Nisha Tailor – Novartis
Patricia Osborne – Brittle Bone Society
Richard Piper – Roald Dahl's Marvellous Children's Charity
Richard Rogerson – Niemann-Pick Disease Group
Sarah Radcliffe – National AIDS Trust
Simon Butler – Anthony Nolan
Simon Wigglesworth – Epilepsy Action
Sophie Cramb – Asthma UK
Tess Harris – PKD Charity
Val Stevenson – Genzyme

John Murray – Secretariat (except for item 13)
Dorothy Chen – Secretariat (ditto)
Andrew Wilkinson – Secretariat (ditto)

1. COMPETITION LAW COMPLIANCE

Members noted their obligations under competition and bribery law.

2. APOLOGIES

A number of apologies had been received.

3. MINUTES

Agreed: amendments to the Minutes of the previous meeting on Wednesday 16th July 2014 to reflect the attendance of Audrey Michniewicz, Caroline Morrice, Nicholas Palmer and Chris Sotirelis. The confirmed Minutes would then be published on the Alliance's website, in line with the Alliance's new governance arrangements, as adopted at the July meeting.

4. MATTERS ARISING

4.1 New members

Reported: that the Anaphylaxis Campaign, Child Lung Foundation and Alstrom Syndrome UK had joined the Alliance, taking its patient-related membership to 105.

4.2 NICE Citizens' Council report on social value judgments

Noted: that the secretariat had submitted a response to the NICE Citizens' Council report on social value judgements on 15th August 2014.

4.3 Chair's advisory group

Agreed: that further details of the Chair's advisory group, including a brief person specification and details of the likely time commitment involved, would be sent to members with a call for expressions of interest.

4.4 Media interest

Reported: that BBC West had been in contact with the Alliance to seek an interview. Members had been consulted about the preferred manner of the Alliance's response with the majority favouring a written statement. Noted: that this resurrected the mistaken theory from earlier in the year that the Alliance got involved in therapy issues and specifically the allocation of resources between radiotherapy and chemotherapy.

Agreed: that the secretariat should provide a written statement to BBC West as approved by members.

5. POLICY UPDATE

5.1 NHS England leadership and structural changes

Considered: that the appointment of Richard Jeavons and the increased capacity of NHS England's specialised commissioning directorate were welcome. However, the transfer of specialised commissioning functions from Area Teams to Regional Teams had the potential to lead to confusion and greater distance from CCGs, as well as a loss of expertise. There was a desire to maintain a robust specialised commissioning presence at Area Team level. More broadly, there was

widespread concern at the extent of continuous change within specialised commissioning. NHS England's desire to undertake structural changes at the same time as setting a new strategic direction for specialised services was thought to be risky.

Agreed: that the secretariat would seek a meeting with Richard Jeavons to discuss his priorities as Director of Specialised Commissioning.

5.2 Five year strategy for specialised services

Reported: that a number of members had submitted A3 proposals and received no reply.

Noted: that in the absence of a response, some members had proactively pursued the proposed service changes in conjunction with other stakeholders.

Considered: that the delayed responses could be indicative of wider confusion in relation to the future structure and capacity of Clinical Reference Groups (CRGs). Reports had emerged that NHS England had intended to enhance the role of CRGs, with the possibility of amalgamating some Groups to form larger and better-resourced organisations. Members were concerned that such an amalgamation might risk crowding out smaller specialised services and could narrow the range of clinical expertise involved in the CRGs. Consequently, some CRGs were also thought to be sceptical of such proposals.

Agreed: that the secretariat would liaise with NHS England for an update on progress in contacting the authors of A3 proposals.

5.3 100,000 Genomes Project

Noted: the report on agenda.

5.4 Derogations report

Reported: that, following repeated delays, NHS England had released preliminary data tables which outlined providers' compliance with national specialised service specifications from last year. The document distinguished between commissioner and provider derogations.

Considered: that NHS England had originally been expected to publish a far more detailed account of provider compliance, including the reasons for any derogations and details of the actions and timelines agreed with providers to bring them into compliance. The absence of such data from the public record was disappointing and limited the usefulness of the information released.

Noted: concerns in relation to the integrity of the compliance data. For some services, the tables appeared not to include data returns from several Area Teams. There were also questions about how compliance was measured for the purpose of this self-assessment.

Agreed: that the Alliance would continue to seek a copy of the detailed derogation report, which had been prepared for publication in early 2014.

5.5 NHS England policy development process

Reported: that NHS England had prepared interim prioritisation tools and associated generic policies. The intention was to use these on a provisional basis for prioritisation from the end of October, with several of the generic policies consulted upon before the end of the year and the overall prioritisation tools expected to be consulted upon thereafter.

Noted: that this was an issue on which the Alliance had campaigned for a number of years and which, though now moving in the right direction (eg with the recognition that a restrictive IFR policy required expeditious development of commissioning policies), remained far from addressed.

Considered: that, while selected stakeholders had been invited to comment on the revised documents, it was unclear whether NHS England would consult on the updated generic policies prior to full implementation. Clear and structured public engagement should be conducted to ensure that the needs of people with rare and complex conditions would be taken into account. The application of the policies also remained a concern, given that Programme of Care Boards and others were being asked to evaluate dozens of proposals per meeting.

Agreed: that the Alliance should continue its efforts to hold NHS England to account in this important field.

5.6 Cancer Drugs Fund and 'evaluation through commissioning'

Considered: that Simon Stevens' proposals to extend 'evaluation through commissioning' was welcome. However, reports had emerged that NHS England was increasingly struggling to meet the 90-day deadline for funding treatments positively appraised by NICE.

6. TASKFORCE SURVEY

Noted: the report on agenda.

7. TASKFORCE REVIEW OF SPECIALISED COMMISSIONING

Reported: that the taskforce had been preparing proposals for NHS England to move towards co-commissioning specialised services with CCGs. The definition of co-commissioning remained unclear. This might range from long overdue collaboration between CCGs and NHS England to more formal pooling of budgets. The Commissioning Intentions document had indicated that co-commissioning would operate in shadow form during 2015/16, with a view to full implementation the following year.

Considered: that, while co-commissioning had potential to improve pathway integrity and prevention efforts, it could muddy accountability between NHS England and CCGs and potentially introduce greater clinical risk. The Alliance had welcomed the development of national service specifications to level up service standards uniformly across the country. The risk was that co-commissioning would permit variation from these specifications, undermining the progress made under the new commissioning arrangements and potentially prejudicing the principles of the Health and Social Care Act in creating a national risk share for

specialised services. Members would be particularly concerned if this was confirmed as NHS England's direction of travel.

Noted: that CCGs could choose the structures and extent of co-commissioning they wished to enter into. This might lead to further variations cross the country.

Agreed: that, given the strength of feeling on co-commissioning and the potential risks posed, the Alliance would continue to press for the need to retain clear accountability and national budget-holding for specialised services. Members endorsed a proactive approach to be taken. In the first instance, the secretariat would write to Earl Howe to raise these concerns.

8. MEETING WITH NHS ENGLAND LEADERSHIP

Noted: the report on agenda.

9. SCOPE OF SPECIALISED COMMISSIONING

Reported: that the Commissioning Intentions 2015/16 had identified several services, currently classified as specialised, which NHS England would favour being devolved to CCGs. These had been submitted to the independent Prescribed Specialised Services Advisory Group, which would provide recommendations to Ministers on whether changes should be made to the regulations prescribing the scope of specialised commissioning.

Considered: that the lack of public consultation on the proposed changes was concerning, particularly in the light of NHS England's proposed direction of travel towards a smaller scope for specialised commissioning. There was a risk that decisions would be driven by a desire to shift responsibility and spend to CCGs rather than to capitalise on the unique opportunities afforded by a single specialised commissioner to improve efficiency and outcomes. Furthermore, there was a lack of clarity on how the process of changing commissioner would work in practice, including the means of transferring appropriate budget and management resource.

10. PARLIAMENTARY ENGAGEMENT

Noted: the report on agenda.

11. SCOTLAND EVENT

Noted: the report on agenda.

12. 2015 PROGRAMME

A presentation was given, reflecting on the Alliance's activities against its 2014 communications plan, and suggesting priority areas for engagement in 2015.

Considered: that the presentation outlined a sensible set of priorities to guide the Alliance's work in 2015 alongside its core activities. Members supported the Alliance's strategic positioning and desire to focus its resources on areas in which it could make the greatest impact. In taking forward the work programme, the Alliance would retain flexibility in taking on a more public position in relation to specialised commissioning.

Noted: that the Alliance's 14 corporate members were minded to maintain their support for 2015 at the same level as in 2014. However, some uncertainty surrounded potential corporate mergers.

Agreed: that the secretariat would share the presentation slides with members for further written comments, before preparing a more detailed communications plan for 2015 for agreement by written procedure.

13. APPOINTMENT OF SECRETARIAT

Agreed: that JMC Partners would be retained as the Alliance's secretariat in 2015.

14. LUNCH GUEST

Professor Sir Ian Gilmore, Chair of the Prescribed Specialised Services Advisory Group (PSSAG), would be the Alliance's lunch guest.

15. REPORT ITEMS

Report items were noted as per the notes on agenda.

15.1 National Voices' Person Centred Care 2020

15.2 NHS England Annual General Meeting

15.3 Patient and Public Voice Assurance Group

15.4 HSJ Article

15.5 Ann Sutton meeting

15.6 Teenage Cancer Trust events

15.7 Specialised services in Wales

15.8 Meetings during July to October

16. DATES OF NEXT MEETINGS

Reported: that suggested dates for the Alliance's quarterly meetings in 2015 were yet to be confirmed.

Agreed: that the secretariat would notify members of future meeting dates as soon as the Parliamentary recess dates for 2015 were published.

17. ANY OTHER BUSINESS

The Chair closed the meeting at 11:45am.