

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 10.00AM – 12.00PM ON
WEDNESDAY 15th JULY 2015 AT 21 ARLINGTON STREET, LONDON, SW1A 1RN**

Present:

Baroness Wheeler – Chair

Aaron Revel – Action Duchenne
Andy Barrick – MSA Trust
Caroline Morrice – GAIN
Chloe Kastoryano – Scleroderma Society
Chris Sotirelis – UK Thalassaemia Society
Conn O’Neill – National Rheumatoid Arthritis Society
David Ryner – CML Support Group
Fiona Campbell – Bayer
Gary Jones – Abbvie
Gordon McFadden – United Amputees Community Charity
Janet Mills – Save Babies UK
Jerome Penn – Pfizer
Keyan Salarkia – Macmillan Cancer Support
Larushka Mellor – Merck Serono
Laura Courtney – CLIC Sargent
Lesley Harrison – AKU Society
Liz Bevins – Raynauds and Scleroderma Association
Miguel Souto – British Society for Rheumatology
Nisha Tailor – Novartis
Simon Butler – Anthony Nolan
Simon Wigglesworth – Epilepsy Action
Steve Bojakowski – Sobi

John Murray – SHCA
Andrew Wilkinson – SHCA
Catherine Kilkenny - 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.

Noted: that the meeting venue had been changed at short notice due to developments at the House of Lords.

3 MINUTES

Agreed: the minutes of the last meeting on Wednesday 15th April 2015. The minutes would duly be published on the Alliance's website.

4 MATTERS ARISING

4.1 New members

Reported: As per the notes on agenda.

4.2 Meeting with NICE

Reported: as per the notes on agenda.

Noted: disappointment at the absence of many members who had registered to attend. NICE had nevertheless twice emphasised how useful it had found the meeting.

Considered: that attendees had found it helpful to discuss the lack of consistency in the approach to evaluating specialised technologies between the various appraisal routes across NICE and NHS England. The question of affordability continued to be raised in broader policy discussions and ambiguity on this score was of concern to members and a potential cause of current tension between NICE and NHS England.

Agreed: to return to these discussions under agenda item eight on the Accelerated Access Review.

5 POLICY UPDATE

5.1 NHS England personnel

Reported: as per the notes on agenda.

Noted: that following Dame Barbara Hakin's retirement, the evolution of the National Director for Commissioning Operations role would be of particular interest given its overall responsibility for specialised commissioning.

5.2 Scope of specialised commissioning

Reported: that, given NHS England's desire to reduce the scope of specialised commissioning the previous year, and hints from the Chief Executive of NHS England that further proposals for changes could be brought forward in this financial year, the secretariat had communicated with the secretariat of the

Prescribed Specialised Services Advisory Group which advised Ministers on the scope of specialised services.

Noted: that NHS England officials had suggested in recent weeks that they were unlikely to propose substantial changes to the scope of specialised commissioning this year but that, elsewhere, work was ongoing to review the level at which services were commissioned.

Considered: that the response from PSSAG had been disappointingly vague on its process for receiving and considering future proposals for change. PSSAG appeared reliant on NHS England to conduct engagement, with potential prejudice to PSSAG's ability to form a fully informed view.

Agreed: that the Alliance should follow up with the Chair of PSSAG directly to communicate members' desire to see PSSAG conduct its own, transparent engagement when considering proposals and seeking further information.

5.3 NHS finances

Reported: as per the notes on agenda.

Noted: that other discretionary funds within NHS England were overspent and could pose further challenges to the specialised budget.

5.4 Parliamentary Updates

Reported: as per the notes on agenda.

6. NHS ENGLAND PRINCIPLES AND PROCESSES FOR SPECIALISED SERVICES

6.1 Consultation on 'investing in specialised services'

Reported: that while NHS England had conducted substantial engagement during the consultation on prioritisation principles, its formal consultation response was remarkably brief and did not address the key issues raised by consultees in any detail. The Patient and Public Voice Assurance group, of which the SHCA was a member, was being asked formally to assure the process.

Noted: that the Alliance might wish to liaise with National Voices regarding members' general dissatisfaction about the absence of meaningful consultation across specialised commissioning.

Considered: that while the consultation process itself had been comprehensive and proactive on the part of NHS England, members considered the final consultation outputs to have been below the standard required. In particular, members were disappointed to see so few changes made or even acknowledged in the prioritisation principles adopted following the consultation and 278 submissions. In view of these deficiencies, members were keen for the Alliance to take a firm line in withholding support for the consultation as a whole. The potential re-introduction of a 'scorecard' system for assessing future proposals within specialised services was also a cause for concern and should be monitored in future.

Agreed: that the Alliance could not endorse the quality of the prioritisation consultation at the Patient and Public Voice Assurance Group owing to concerns on the quality of NHS England's consultation output.

6.2 Policy development process

Reported: that further to the notes on agenda, the secretariat would be meeting Richard Jeavons, Director of Specialised Commissioning and James Palmer, Clinical Director Specialised Services, to discuss changes to NHS England's policy development process.

Noted: that the introduction of a new 'clinical review panel' within NHS England's specialised commissioning policy development process might make the system more complex, not less, to the disappointment of members.

Considered: that, in endorsing the Alliance's alternative policy development process proposal in their responses to the prioritisation consultation, members had helped encourage NHS England to focus on improving its processes in the months ahead.

Agreed: that the secretariat would engage with NHS England and report back to members on progress.

6.3 NHS England decisions on specialised commissioning policies

Reported: that the publication of NHS England's decisions on a range of policies on 1st July had been a milestone in the sense that the backlog of these decisions had been building up for a long period. The secretariat understood that specialised commissioners were particularly keen to meet stakeholders who were disappointed by the decisions affecting them.

Noted: that a further circular from NHS England had listed proposals to be developed by NHS England for 2016/17. There had been less public attention on these topic selection decisions.

Considered: that NHS England had proactively engaged patients groups and others to discuss negative commissioning decisions, which had been appreciated by members. However, the continued absence of published committee meeting papers undermined these discussions somewhat, given that the reasoning of decisions remained unavailable. Members were keen for NHS England to be pushed on the need for greater transparency in these matters. The framing of draft consultation documents had also proven problematic, as all had been issued as positive recommendations, leading many stakeholders to submit short responses endorsing the draft policy, rather than arguing robustly for its adoption.

Agreed: that the secretariat would communicate members' feedback on their experiences with these individual decisions in the upcoming meeting with Richard Jeavons and James Palmer.

6.4 Interim access for patients in urgent critical need

Reported: that the Alliance had campaigned on this issue for some time and that the published Standard Operating Procedure for Clinically Critically Urgent Cases raised a number of important questions for members to consider.

Noted: that members' individual campaigning had also helped to raise the

prominence of this issue with the media and elsewhere.

Considered: that the SOP published by NHS England was significantly different in its provisions from the previous Specialised Services Circular on interim treatment access, as used in 2013. The previous policy had prioritised individual patient need, whereas the new SOP seemed geared towards the development of interim national commissioning positions, with ambiguous evidence and cost-effectiveness thresholds. Of particular concern was that, while the SOP was intricately linked to other generic policies, such as that for Individual Funding Requests, it would not be consulted upon publicly like the others. Members considered it important for the procedure to be public scrutinised and for it to prioritise the needs of patients in urgent need, rather than cohorts. In making its case, the Alliance would require examples of the policy's successes and failings in practice, though remaining mindful of the Alliance's principle of non-involvement in individual therapy areas.

Agreed: that the Chair would write to Sir Bruce Keogh to communicate members' dissatisfaction at the SOP. Members would also provide the secretariat with any examples of the policy's use in practice.

7. COLLABORATIVE COMMISSIONING

7.1 Policy developments

Reported: that recent updates from NHS England, and a recent reply from the Minister for Life Sciences to a letter sent by the Alliance's Chair, had implied that plans to move towards sharing responsibilities for specialised services with local Clinical Commissioning Groups had been scaled back, as per the Alliance's desire to see collaboration without muddying of responsibilities or pooling of budgets.

Considered: that the Alliance's campaign on this issue had been effective in clarifying the rationale for national budget-holding for specialised services and ensuring that clear accountabilities would be retained. However, further changes in policy were still possible and the Alliance would need to remain watchful and engaged.

Agreed: that the secretariat would circulate the Minister's letter to members.

7.2 Letter to party leaders

Reported: as per the notes on agenda.

7.3 DevoManc and specialised services

Reported: that while the Alliance appeared to have won much of the argument on collaborative commissioning within specialised commissioning, broader devolution policy across government had the potential negatively to impact specialised services.

Considered: that the House of Lords was considering the Cities and Local Government Devolution Bill, provisions of which would allow NHS organisations to share or devolve aspects of their commissioning decisions to local partnership organisations. This could enable deviation from national service specifications and clinical commissioning policies within specialised services, subject to the passage of the legislation. The Director had been in touch to outline the

Alliance's principles on this matter to Lord Warner who had tabled amendments on devolution of NHS responsibilities.

Agreed: that the Alliance should monitor and engage with the passage of the legislation through the House of Commons after the summer recess, with an assessment of its potential impact on specialised services. The secretariat would prepare a briefing for members on the issue for their use with parliamentarians at the same time.

8 ACCELERATED ACCESS REVIEW

Reported: that the secretariat had previously been informed by the Office for Life Sciences, which was leading the Accelerated Access Review (AAR), that NHS England's specialised commissioning appraisal processes would not fall within its scope. The Director had made further enquiries on this score, including a question to the Minister for Life Sciences on this subject at a recent engagement event. Subsequently, those involved with the review, including its Chair, Sir Hugh Taylor, appeared to show a greater recognition of the need for further scrutiny of these processes.

Noted: that the Alliance's queries on the scope of the review may have been helpful in communicating the importance of including NHS England's specialised commissioning processes.

Considered: that the AAR would be launching its 'crowdsourcing' process shortly to seek views on improving the speed and fairness of innovation uptake within the NHS. The Alliance might usefully prepare a response in relation to the issues within specialised commissioning in order to ensure their consideration within the review. This could also include material on the gap between NHS England and NICE processes. Given the crowdsourcing approach and alongside its own full submission, the Alliance could also provide material to feed in to members' individual submissions, maximising the impact of the arguments across the membership.

Agreed: that the secretariat would draft an Alliance response to the AAR and share it with members for comment and approval. Draft content for members' own use would also be shared with members for use.

9 SHCA CONFERENCE

Reported: the Chair considered that the Alliance's conference, which had taken place the day before, had been a success and that the late apologies from Sir Bruce Keogh had not undermined an otherwise very strong line-up of speakers.

Noted: that discussion of specialised care payment systems at the conference indicated the need for the Alliance to maintain its monitoring of this area given the potential impact on patient access to services and particularly on the use of specialised treatments. The Alliance's strong relationships with NHS Providers and NHS Clinical Commissioners had been helpful in cascading information about the conference to a broad spectrum of stakeholders but this had not translated into high attendance levels on the day.

Considered: that while the attendance levels had been lower than expected given the strength of the line-up, the day had nevertheless served to bring together a broad range of perspectives on specialised care in order to consider the challenges and opportunities ahead. The presentations had been of a very high quality and the patient speaker had given a particularly valuable perspective.

Agreed: that the secretariat would finalise a report of the conference and circulate this, along with the slides shown on the day, to all members and delegates.

10 SHCA WORKSHOPS AND REPORT

Reported: that the Alliance would be convening three workshop sessions during the second half of the year in order to gather multidisciplinary input into its report.

Noted: that discussions were underway with NHS England following its pledge to assist in the provision of speakers and attendees for the workshops. It would also be important for there to be a strong showing of SHCA members at the events, to be held across the country.

Agreed: that the secretariat would continue to seek NHS England's input for the workshops and that members would provide any further comments on the draft programmes in writing.

11 RARE DISEASE DEVELOPMENTS

11.1 UK Rare Disease Forum report

Reported: that the secretariat had continued to represent the Alliance on the Forum, which was now in the process of preparing a draft of its report to Ministers on progress in implementing the UK Strategy for Rare Diseases.

Noted: that members were encouraged to send through comments on the implementation of the UK Strategy for Rare Diseases to the secretariat for these to be communicated at the next Forum meeting.

Considered: that there were concerns that the devolved administrations might exercise final editorial control over the sections of the report covering their performance and that members were keen for balanced comment to be included in the report.

Agreed: that the secretariat would seek to share as much of the draft report as possible with members and would continue to push for it to be developed independently.

11.2 Westminster Hall debate on access to drugs for ultra-rare diseases

Reported: as per the notes on agenda

11.3 Northern Ireland Rare Diseases Office

Reported: as per the notes on agenda

12 REPORT ITEMS

Report items were taken as per the notes on agenda.

12.1 Health + Care show

12.2 HSJ articles

12.3 NHS Innovation Expo

12.4 Patient and Public Voice Assurance Group

12.5 Meetings during April to July

13 DATE OF NEXT MEETING

Reported: that the Alliance's next quarterly meeting would be held on Wednesday 14th October at 11am in House of Lords Committee Room G.

14 ANY OTHER BUSINESS

Reported: that NHS England was holding a series of workshops on co-commissioning for Clinical Commissioning Groups and others to attend.