

Specialised Healthcare Alliance

FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 11AM ON WEDNESDAY 14TH
JANUARY 2015 IN THE HOUSE OF LORDS COMMITTEE ROOM G, LONDON SW1A 0AA**

Present

Baroness Wheeler – Chair

Alice Hamilton	MS Trust
Amanda Swain	UK Acquired Brain Injury Forum
Andy Barrick	MSA Trust
Anna Baranski	Macmillan
Brian Gunson	British Liver Trust
Camilla Horwood	Novo Nordisk
Caroline Morrice	GAIN
Chris Sotirelis	UK Thalassaemia Society
Daisy Ellis	Terence Higgins Trust
Dan Beety	Bayer
David Ryner	CML Support Group
Diane Splevings	Shire
Donna O'Brien	SeeAbility
Eve Whitley	AKU Society
Gary Jones	AbbVie
Georgina Grant	Gilead
Grace Everest	Hepatitis C Trust
Helen Kirrane	Bliss
Henrietta Spalding	Changing Faces
John Kell	MND Association
Katie Begg	Anthony Nolan
Lara Bloom	Ehlers-Danlos Syndrome UK
Leo Watson	Parkinson's UK
Liz Bevins	Raynaud's & Scleroderma Association
Luella Trickett	Baxter
Mark Scott	Merck Serono
Matthew Buckland	UKPIN
Morwenna Opie-Moran	PoTS UK
Nick Medhurst	CF Trust
Patrick Ojeer	Sickle Cell Society
Sarah Hutchinson	National Voices
Sarah Radcliffe	National AIDS Trust
Simon Wigglesworth	Epilepsy Action
Tanya Collin-Histed	Gauchers Association
Tess Harris	PKD Charity
Tony Griffiths	St Andrew's Healthcare
Val Stevenson	Genzyme
Laura Wetherly	National Rheumatoid Arthritis Society
Rosanna Preston	CLAPA
Nisha Tailor	Novartis
Richard Rogerson	Niemann-Pick Disease Group
Deb Morgan	Pfizer
John Murray	Secretariat
Andrew Wilkinson	Secretariat
Edward Nickell	Secretariat

1. COMPETITION LAW COMPLIANCE

Members noted their obligations under competition and bribery law.

2. APOLOGIES

The meeting was at full attendance. Members were reminded that it was essential to confirm their attendance in advance with the secretariat.

3. MINUTES

Agreed: the Minutes of the previous meeting on Wednesday 15th October 2014. The minutes would be published on the Alliance's website, in line with the Alliance's governance arrangements adopted at the meeting on Wednesday 16th July.

4. MATTERS ARISING

4.1 New members

Reported: that SeeAbility and the MSA Trust had joined the Alliance, taking its patient-related membership to 108. The Dystonia Society were considering membership, as were Genetic Disorders UK and the Chronic Granulomatous Disorder Society. On the corporate side, NPS Pharmaceuticals and Bayer had joined the Alliance, while InterMune's membership had ended after the company became part of Roche. In total, this brought the SHCA's corporate membership up to 15.

4.2 Letter to Earl Howe

Reported: that the Director's meeting with Earl Howe had been truncated due to parliamentary business but focused on the statutory issues presented by NHS England's proposals on co-commissioning. The Minister had been emphatic in his support for NHS England to retain the specialised commissioning budget, though with the ability both to move services out of specialised commissioning where appropriate and to allow Clinical Commissioning Groups to benefit from underspends in specialised commissioning. Earl Howe had expressed a willingness to continue discussions.

4.3 Chair's Advisory Group

Reported: that the Chair had selected Amanda Swain, Chris Phillips, Nisha Tailor and Sarah Vibert to provide her with ad hoc support and thanked them for volunteering for the role. The group had met and discussed the Alliance's campaign strategy on co-commissioning as well as a proposal that Andrew Wilkinson become Deputy Director of the Alliance.

Agreed: that Andrew Wilkinson should take on the role of Deputy Director for the Alliance.

4.4 Holyrood event

Reported: that the parliamentary reception in Scotland had seen a good turnout from Members and MSPs and that a report of the event had been shared with all members.

Noted: that in the week following the event, a reshuffle of the Executive by the new First Minister Nicola Sturgeon had seen Shona Robison appointed as the new Cabinet Secretary for Health and Wellbeing.

Agreed: that the Alliance would write to Shona Robison by way of introduction and to communicate the output of the event.

4.5 BBC West Programme

Noted: the report on agenda.

5 POLICY UPDATE

5.1 NHS England appointments

Noted: the report on agenda.

5.2 NHS England policy development processes

Reported: that James Palmer, Clinical Director Specialised Services at NHS England, had approached the Alliance seeking members' views on proposed changes to NHS England's policy development processes.

Considered: that a two hour workshop with members would be a suitable format.

Agreed: to arrange a date for the event, ideally held towards the end of the month.

5.3 Specialised Taskforce

Noted: the report on agenda.

5.4 NHS England finances

Reported: that NHS England's financial difficulties had continued since the last meeting, but an injection of extra funding from the Government would see the specialised commissioning overspend eliminated for 2015/16. The new baseline budget for specialised commissioning would be £14.6billion.

Noted: that NHS England had published notional allocations of the specialised commissioning budget for each individual CCG. This demonstrated that the vast majority of specialised services would be under consideration for co-commissioning, with only £1.08billion allocated for expressly national commissioning of highly specialised services, together with the Cancer Drugs Fund.

Considered: that the adjustment of the budget baseline had not addressed some of the underlying cost drivers which had contributed to the overspend. There was little reason to believe that the definition and composition of highly specialised services would be significantly changed.

Agreed: that the secretariat would circulate a list of the highly specialised services to members for reference.

6. PRIORITISATION CONSULTATION

Reported: that NHS England's ongoing failure to develop a robust ethical framework for its decision-making had continued to cause difficulties, culminating in a legal challenge to its processes towards the end of 2014. In order to form a robust and legitimate decision-making (or prioritisation) framework, NHS England's Board decided at its December meeting to open a 90 day consultation on principles to underpin a new framework.

Noted: that the Alliance had raised concerns with the prioritisation framework over the last three years and the most recent problems had been widely expected after discouraging feedback from Programme of Care Board meetings in October.

Considered: that while a full consultation period would provide a welcome opportunity to comment on NHS England's ethical principles, there was significant concern about the delay that such a consultation would cause to commissioning policies. Given the need to incorporate feedback following the consultation, which had not yet opened, a new framework was unlikely to be in place until May or June at the earliest. In the meantime, only urgent or emergency changes to services or treatment policies would be authorised by NHS England. No other interim arrangements were in place and patient care and access could be compromised. In most cases, Individual Funding Requests would not provide an alternative route for funding. The Alliance could usefully seek assurances on interim arrangements to support improvements in patient care.

Agreed: that the Alliance would write to Sir Bruce Keogh to highlight members' concerns on the delays caused by the prioritisation consultation. In particular, the correspondence would seek firm commitments on both interim access arrangements and the procedures in place to deal with the policy backlog when a new framework is finalised. The secretariat would also engage Chairs of Clinical Reference Groups to see if they were similarly minded to write to the Medical Director.

7. CO-COMMISSIONING CAMPAIGN

7.1 Policy Developments

Reported: that while NHS England's plans for co-commissioning specialised services remained opaque, the Alliance had prepared a 'primer' which assembled the evidence to date. This demonstrated a clear direction of travel towards the pooling of budgets for specialised services with Clinical Commissioning Groups from April 2016.

Noted: that in its messaging the Alliance would need to emphasise its support for collaborative commissioning without pooling of budgets. There was little certainty about what the status of clinical commissioning policies and national service specifications would be under future co-commissioning models, presenting clear risks to Alliance members.

Considered: that recent policy documents produced by Clinical Commissioning Groups had emphasised their autonomy in relation to their commissioning responsibilities. In order to ensure consistent national service specifications and clinical commissioning policies remained in place in future, the essential question would be whether NHS England remained the sole budget holder for specialised services beyond 2015/16.

7.2 Campaign strategy

Reported: that in taking forward the co-commissioning campaign, a strategy had been shared with members for input and a small 'action group' formed, comprising members able to provide case studies and media spokespeople at short notice.

Noted: that any members wishing to join the action group should contact the secretariat.

Considered: that the strategy would encompass meetings with a range of health organisations, some of which had already taken place. Political engagement would be crucial, along with targeted media activity.

Agreed: to proceed with the strategy as circulated to members.

8. POLITICAL ENGAGEMENT

Reported: that Stephen Gilbert, Liberal Democrat MP for St Austell and Newquay, had secured a three hour debate on national commissioning of NHS specialised services in Westminster Hall. The debate was to take place between 13.30 and 16.30 on Thursday 15th January. The Alliance had prepared briefing on specialised services and co-commissioning which had been circulated to members and MPs. Alliance members had also been asked to contact MPs to encourage debate attendance.

Considered: that the debate was a crucial component of the Alliance's parliamentary strategy, not least in the context of the co-commissioning campaign. It would provide a timely opportunity to discuss the issues facing specialised services ahead of the General Election. The biggest risk was that the debate would be poorly attended, given that many MPs returned to their constituencies on a Thursday afternoon if not before.

Noted: the Alliance's other meetings with parliamentarians, as reported in the notes on agenda.

Agreed: that members should encourage MP supporters to attend the debate.

9. SCOPE OF SPECIALISED COMMISSIONING

Reported: that a consultation on the potential devolution of some specialised services to Clinical Commissioning Groups was ongoing and that the Alliance had submitted a short response focusing on the need for robust processes and smooth transitions in the event of changes to commissioning responsibilities.

Considered: that given the strong opposition of the renal community to the proposed changes, as well as the short timeframe over which devolution of services was planned, it seemed possible that devolution of bariatric surgery and dialysis would be deferred for a year. These matters were of broader significance across the Alliance's membership, given the precedents being set in changing commissioning responsibilities, where improved transparency and rigour was required.

10. CHANGES TO NATIONAL TARIFF FOR SPECIALISED SERVICES

Reported: that changes recently proposed by NHS England and Monitor to how providers are reimbursed for delivering specialised services were of potential significance to the Alliance. In proposing a 50% 'gain-share', the proposals would introduce a strong incentive for providers to reduce specialised activity significantly and seemed to work against the concentration of services in centres providing the best outcomes. Insofar as the proposals would impact patient access, the Alliance had made its concerns known in response to the consultation.

Noted: that the Alliance had requested sight of NHS England's impact assessment for these proposals in order to assess the potential risks.

Considered: that there seemed to be little sign of compromise between NHS England and providers on this issue and the Alliance would wish to monitor developments closely. Either NHS England or providers ran the risk of budget deficits if they conceded ground. The inclusion of drugs and medical devices within the scope of this proposal was particularly concerning. NHS England had previously indicated that new NICE Technology Appraisals would be exempt.

Agreed: that the Alliance would continue to monitor developments on the gain-share proposals and alert members to any changes.

11. UK STRATEGY FOR RARE DISEASES

Reported: that the Alliance continued to participate in the Department of Health's UK Rare Disease Forum, which had been formed to monitor the implementation of the UK Strategy for Rare Diseases in each of the devolved administrations. While work was underway at Public Health England to build a registry for rare diseases, there was little sign of further activity on the rare disease strategy within NHS England. Elsewhere, Scotland, Wales and Northern Ireland had published detailed implementation plans for public consultation.

Noted: that further information on the activities and engagement opportunities in each devolved nation were available from the secretariat on request.

Agreed: that members wishing to input views into future meetings of the Forum should contact the secretariat.

12. LUNCH GUEST

Reported: that Richard Jeavons, Director of Specialised Commissioning at NHS England, had been planning to join members over lunch but was called away at short notice. James Palmer, Clinical Director Specialised Services would join in his place.

Considered: that members would still benefit from meeting Richard to discuss the formation of the specialised commissioning directorate.

Agreed: to seek a members' meeting with Richard Jeavons at the earliest opportunity.

13 REPORT ITEMS

Report items were noted as per the notes on agenda.

14. DATE OF NEXT MEETING

The Alliance's next quarterly meeting would be held on Wednesday 15th April at 11am in the House of Lords Committee Room G.

15. ANY OTHER BUSINESS

The Chair closed the meeting at 11.45am