

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 10:30AM ON WEDNESDAY  
15<sup>th</sup> APRIL 2015 IN CONFERENCE ROOMS A&B, JONES DAY, 21 TUDOR STREET,  
LONDON, EC4Y 0DJ**

**Present:**

Alex Massey – Neurological Alliance  
Andy Barrick – MSA Trust  
Anna Lewis – British Society for Rheumatology  
Anne Keatley-Clarke – Children's Heart Federation  
Blimpe Joseph – Actelion  
Brian Gunson – British Liver Trust  
Caroline Morrice – GAIN  
Chris Sotirelis – UK Thalassaemia Society  
Danielle Stevenson – Myrovlytis Trust  
Debra Morgan – Pfizer  
Diane Splevings – Shire  
Dominic Pivonka – Abbvie  
Eve Whitley – AKU Society  
Fiona Campbell – Bayer  
Fiona Loud – British Kidney Patients Association  
Georgina Grant – Gilead  
Gordon McFadden – United Amputees Community Charity  
Grace Everest – Hep C Trust  
Henry Featherstone – Genzyme  
Hilary Tovey – British Lung Foundation  
John Kell – Motor Neurone Disease Association  
Katherine McIntosh – Epilepsy Society  
Laura Courtney – CLIC Sargent  
Liz Bray – The Children's Trust  
Lynne Regent – Anaphylaxis Campaign  
Maggie Burcham – Rarer Cancers Foundation  
Mark Bell – SOBI  
Nick Medhurst – Cystic Fibrosis Trust  
Nicola Ritchie – Baxter  
Patricia Osborne – Brittle Bone Society  
Richard Rogerson – Niemann-Pick Disease Group  
Sara Hunt – ALD Life  
Sarah Hutchinson – National Voices  
Sarah Radcliffe – National AIDS Trust  
Sasha Daly – Teenage Cancer Trust  
Simon Butler – Anthony Nolan  
Sophie Cramb – Asthma UK  
Tamara Sandoul – British Lung Foundation  
Vinay Mistry – Novartis

John Murray – Secretariat (in the Chair)  
Andrew Wilkinson – Secretariat  
Arnaud Siad – Secretariat  
Catherine Kilkenny – Secretariat

## **1. COMPETITION LAW COMPLIANCE**

Members noted their obligations under competition and bribery law.

## **2. APOLOGIES**

Reported: that a number of apologies were received. In particular, the Chair was unwell with flu and therefore unable to attend. She had agreed that the meeting proceed in her absence.

Noted: that owing to the parliamentary recess, the Chair had been unable to secure a room for the meeting on the parliamentary estate. A trustee of the Brittle Bone Society had kindly offered the conference room at Jones Day instead, for which Alliance members were grateful.

Agreed: that the Director would chair the meeting and pass on members' appreciation to Jones Day.

## **3. MINUTES**

Agreed: the minutes of the Alliance's previous meeting on Wednesday 14<sup>th</sup> January 2015. The minutes would be published on the Alliance's website.

## **4. MATTERS ARISING**

### **4.1 New members**

Reported: that Genetic Disorders UK, the Chronic Granulomatous Disorder Society, the Batten Disease Family Association, the United Amputees Community Charity, Together for Shorter Lives and ALD Life had all joined the Alliance, taking its patient-related membership up to 112. Sobi had also joined the Alliance as its 16<sup>th</sup> corporate member.

### **4.2 Meeting with Paul Streets OBE**

Noted: as per the notes on agenda.

## **5. POLICY UPDATE**

### **5.1 NHS England appointments**

Reported: as per the notes on agenda.

Noted: that the Alliance continued to await a full diagram of the new appointments within the specialised commissioning directorate.

### **5.2 NHS England consultations**

Reported: that NHS England was consulting on a range of specialised service specifications and clinical commissioning policies, in order to be in a position to sign these off shortly after the close of the prioritisation consultation at the end of April.

Noted: that the concerns communicated by the Alliance on the risk of delays to policy development arising from the prioritisation consultation may have helped encourage NHS England to mitigate the problem through this early consultation.

Considered: that notwithstanding the accelerated consultation process, there remained concerns that such policies would not be signed off until June or July, given the other NHS England processes which would need to be followed.

### **5.3. Scope of specialised commissioning**

Reported: that changes to the scope of specialised commissioning had been a key topic of discussion at recent Alliance meetings. As reported in the notes on agenda, Ministers had ultimately deferred the devolution of morbid obesity services until April 2016, with no decision on whether or not to devolve renal dialysis in future.

Considered: that the clear direction of travel for specialised commissioning was for its scope to be reduced, with NHS England having resisted the addition of new services to its remit this financial year. The devolution of morbid obesity services would be of potentially broader interest, given the precedent for other services in line for future devolution.

### **5.4 NHS England finances**

Reported: NHS England's updated financial position as per the notes on agenda.

Noted: that uncertainty remained on whether budget deficits would be transferred to local commissioners if services were devolved in future.

Considered: that while the reduced deficit for the year was welcome, NHS England had previously described extra funding for specialised services as a 'catch-up' rather than a 'look forward', meaning that underlying cost drivers would result in larger deficits in future if current trends continued.

### **5.5 Devo Manc**

Reported: that the devolution of health and care budget to Greater Manchester could be of interest to the Alliance. The associated Memorandum of Understanding stated that some specialised services would continue to be commissioned at a national level for Greater Manchester. This probably related to those services classified as 'highly specialised', with less certainty on how other specialised services would be managed. Formally, budgetary arrangements would remain the same, unless the next Government introduced legislative changes.

Noted: that this raised the question of whether Greater Manchester would be able to opt out of national standards for services. There could be benefit in allowing Greater Manchester the flexibility to set its own standards for specialised services if this helped secure genuine integration, but the risks to standards and funding previously highlighted by the Alliance were also significant.

Considered: that this would be a significant issue for the Alliance to engage with in the coming months. Until further information on the detail of DevoManc was available, the Alliance would be unable to take a collective view on its merits.

Agreed: that the secretariat would seek to gain further information about the DevoManc plans at a meeting with Jon Rouse on the 27<sup>th</sup> April, reporting back to members. Further enquiries would also be made.

## **6 PRIORITISATION CONSULTATION**

### **6.1 Consultation response**

Reported: that the SHCA had submitted a response to NHS England's prioritisation consultation, which included detailed comments on the proposed principles. It also criticised unacceptable delays in launching the consultation. The response highlighted the need for clarification in much of the wording and the urgent need to consult on the broader suite of generic policies.

Noted: that the response was available on the SHCA's website.

Considered: that NHS England needed to consult on both the principles and processes for its policy development and that the absence of the latter from the consultation was a major weakness. NHS England's draft plans for a new process, as shared with Alliance members, seemed to complicate rather than simplify the existing system.

Agreed: that the secretariat would enquire further about the nature of NHS England's report and response to the prioritisation consultation.

### **6.4 Policy development process – item taken earlier on agenda**

Reported: that NHS England's policy development process remained a longstanding concern for the Alliance. Richard Jeavons, NHS England's Director of Specialised Commissioning, had asked the Alliance to propose a more streamlined process to inform NHS England's thinking but, having received the Alliance's proposal, NHS England seemed to be pressing ahead with its original, complex plans regardless.

Considered: that members had long called for a policy development process that was timely and transparent as well as robust. The current process relied heavily on Clinical Reference Groups (CRGs) which, as unresourced voluntary bodies had performed variably. There were concerns that clinicians volunteering their time in CRGs were losing faith in the process and beginning to drop out. Reforms to expand CRG membership also led to concerns about their manageability and whether the patient voice on CRGs would be diluted.

Agreed: that the Director would write to Richard Jeavons emphasising the importance members place on this issue and requesting an urgent, formal response to the Alliance's policy process proposal.

### **6.2 NHS England policy backlog**

Noted: as per the notes on agenda.

### **6.3 Interim treatment access**

Reported: that the Alliance had continued to raise the absence of an interim funding mechanism for specialised services awaiting a national policy in a variety of fora. In particular, NHS England had still not responded to the Chair's letter on this issue, despite continued chasing.

Noted: that the absence of an interim funding mechanism presented an acute problem given NHS England's inability to sign-off national policies during the prioritisation consultation, but that even after the close of the consultation the problem would persist, given the time taken to develop national policies more

generally.

Considered: that the Patient Public Voice Assurance Group had flagged this up as an issue in a letter to NHS England and was also still awaiting a reply. Members felt that the urgency of the issue merited further and more robust communication with NHS England.

Agreed: that the Alliance would write a further letter to Sir Bruce Keogh on the interim access issue.

## **7 COLLABORATIVE COMMISSIONING**

### **7.1 Parliamentary debate**

Noted: as per the notes on agenda.

### **7.2 Policy developments**

Reported: as per the notes on agenda.

Considered: that there remained substantial uncertainty on what collaborative commissioning might mean for specialised services in future. In particular, NHS England had conspicuously avoided any commitments on how budgets would be held and managed beyond 2015/16 and had described the year as 'transitional'. The concern remained that full collaboration with local CCGs would enable them to deviate from national standards for specialised care, resulting in a postcode lottery and returning to the historic deprioritisation of smaller patient populations within local planning systems.

Noted: that a recent parliamentary answer had suggested that the Patient and Public Voice Assurance Group (PPVAG) had been involved in the development of NHS England's collaborative commissioning guidance. To the contrary, the PPVAG had not seen the guidance until it was ready for publication, an issue which the Alliance had raised with the PPVAG, urging its Chair to remind NHS England of the importance of accuracy in these matters.

### **7.3 Letter to party leaders**

Reported: that the continued importance of Ministerial decisions was clear in relation to the collaborative commissioning issue, which could require legislative changes to be introduced. The Alliance's letter to party leaders had been signed by a broad range of members.

Noted: that formally each of the main political parties supported national commissioning for specialised services.

Agreed: that the Alliance should engage with new Ministers at the earliest opportunity following the election, with particular regard to collaborative commissioning.

### **7.4 Remaining questions**

Reported: as per the notes on agenda.

## **8 SHCA CONFERENCE**

Reported: that the Alliance's workplan for 2015 included a major conference on specialised care, the fourth in a biennial series. Members had agreed that this should ideally be scheduled in the aftermath of the General Election, recognising that this also introduced some risk in relation to how quickly a Government might be formed.

Noted: that the Alliance planned to approach the next Minister with responsibility for specialised services as quickly as possible after their appointment in order to secure their attendance.

Considered: it was suggested that the next conference could examine how quality and equity of specialised services would be maintained across the country alongside local integration. The conference might have more of a political focus than previous conferences, which had tended to focus on commissioners. Should the political cycle not be conducive to a successful conference with a strong speaker line-up, members considered it better to delay from July rather than press ahead regardless.

Agreed: that the delegate price would be set at £100 for members and NHS employees and £450 for non-member companies and that a July date would be worked towards, retaining the flexibility to postpone if necessary.

## **9 SHCA REPORT**

Reported: that the Alliance would be developing a major report this year as part of its work programme. The intention was to gather and articulate a consensus view for the specialised community on what action would be required over the course of the next parliament. The report would aim to draw together a range of stakeholders, from patients, their representatives, providers, Royal Colleges, industry and elsewhere, to develop a vision for the future of specialised services and clear recommendations for realising this. The aim would be to publish the report between October and November 2015.

Considered: that the report should set out the principles against which the NHS would be measured during the next parliament. Picking up on current Alliance policies, there were likely to cover accountability, innovation, integration, equity and consistency for specialised services. The Alliance would conduct a series of workshops aiming to develop a future vision of the future and to draw out ideas regarding potential solutions. The workshops could be held in three regions: the North, the South and the Midlands. The report would aim to retain as much leeway as possible in order to account for the changing political environment.

Noted: that the uncertainties surrounding the General Election outcome could lead to the context for the report changing substantially.

Agreed: that the secretariat would prepare a draft outline of the SHCA report proposals for member comments before putting an agreed plan into action.

## **10 CHANGES TO NATIONAL TARIFF FOR SPECIALISED SERVICES**

Reported: that further to the notes on agenda, the Alliance had continued to

follow up with Paul Baumann's office for a reply to the Chair's letter expressing member concerns on the tariff proposals.

Considered: that it would be important to monitor the impact of the tariff developments on patients. Members could report these to the secretariat as they arose. In particular, members suspected that the greatest challenges would fall closer to year-end, given the provision for a whole-year baseline level for activity.

Agreed: that members would share their experiences of the impact of the tariff changes with the secretariat and that the Alliance would continue to communicate its concerns on this subject.

## **11 UK RARE DISEASE DEVELOPMENTS**

Reported: that further to the notes on agenda, there were opportunities for members to feed in to the Alliance's contributions to the UK Rare Disease Forum and Scottish Rare Disease Implementation Oversight Group.

Noted: that the ongoing work to establish a registry for rare diseases in the UK was welcome given the Alliance's longstanding support for registers as a means of improving the planning and ultimately the outcomes of specialised services.

Considered: that despite this interest in registers, the Alliance's continued membership of the UK Rare Disorders Registry Advisory Group was of questionable value, given that the group was mostly formed of arms-length governmental organisations focused on the operational details of rolling out a national registration service.

Agreed: that the SHCA would withdraw from the Rare Disorders Registry Advisory Group while offering to contribute in future in the event of patient-related queries. The secretariat would be in touch with members to remind them to input into the Alliance's contribution at the UK and Scottish rare disease group meetings.

## **12. LUNCH GUEST**

Reported: that Jem Rashbass, Director for National Disease Registration at Public Health England and former Director for Cancer Registry Modernisation would be the Alliance's lunch guest.

A note of the lunch discussion is attached as an appendix.

Considered: potential lunch guests for the remainder of the year. Suggestions included members of the Five Year Forward View team, potentially including NHS England's National Director for Commissioning Strategy, Ian Dodge, a range of Programme of Care leads alongside Richard Jeavons as Director of Specialised Commissioning, or representatives from the social care sector to discuss integration.

Agreed: that the secretariat would contact potential lunch guests for the remainder of the year.

## **13. REPORT ITEMS**

Report items were noted as per the items on the agenda.

**14. DATE OF NEXT MEETINGS**

Reported: that the Alliance's next quarterly meeting would be held on Wednesday 15<sup>th</sup> July at 11am.

**15. ANY OTHER BUSINESS**

**The Director closed the meeting at 12:30.**