

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 11.00AM – 2.00PM ON
WEDNESDAY 12th OCTOBER 2016 AT ARCHBISHOP'S ROOM, MILLBANK HOUSE,
WESTMINSTER**

Present:

Baroness Wheeler – Chair
Lord Sharkey – Vice-Chair
Baroness Redfern – Vice-Chair

Steve Bojakowski – Sobi
Amy Bowen – MS Trust
Caroline Brocklehurst – Teenage Cancer Trust
Simon Butler – Anthony Nolan
Joseph Cliff – Asthma UK
Jeff Courtney – Haemophilia Society
Jack Feinmann - BSR
Jeremy Felvus – Pfizer
Tom Griffiths – Communication Matters
Brian Gunson – British Liver Trust (until item 11)
Fiona Loud – British Kidney Patients Association
Sarah Love-Jones – British Pain Society
Alex Massey – Neurological Alliance
Caroline Morrice – GAIN
Mary-Beth Peddell – Novartis
Richard Rogerson – Niemann Pick UK
David Ryner – CML Support Group
Ciaran Scott – AKU Society
Diane Splevings – Shire
Laura Swinburn – Baxter
Huw Thomas – Novo Nordisk

John Murray – SHCA
Andrew Wilkinson – SHCA
Mark Loughridge - SHCA

1. COMPETITION LAW COMPLIANCE

Members and corporate supporters 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 13th July 2016, which would now be published on the Alliance's website.

4. MATTERS ARISING

4.1 New Chair

Reported: as per notes on agenda

Noted: that following three years in office, Baroness Wheeler would be stepping down as Chair but was keen to continue to support the Alliance as a Vice Chair. Baroness Wheeler noted her particular pleasure at the cross-party nature of the SHCA's officers and was committed to facilitating a smooth handover.

Considered: that Lord Sharkey, Vice-Chair of the Alliance, should succeed Baroness Wheeler as Chair from January 2017.

Agreed: that Lord Sharkey would succeed Baroness Wheeler as Chair. Lord Sharkey thanked members for their approval and Baroness Wheeler for her dedicated service to the Alliance.

4.2 New secretariat

Reported: as per notes on agenda

Noted: that the outgoing secretariat was committed to facilitating an orderly transition to a new agency in the months ahead. The Chair wished to record her gratitude for the secretariat's 13 years of service to the Alliance.

Considered: that the main priority for the Alliance would be to have a strong new secretariat ready to take over from 1st January 2017.

4.3 New member

Reported: that WMUK had joined the SHCA, taking patient-related membership up to 121.

5 POLICY UPDATE

5.1 Personnel changes

Reported: that, in addition to the notes on agenda, the publication of the Accelerated Access Review, now the responsibility of Lord Prior of Brampton, Minister for Health, was still awaited.

5.2 NHS finances

Reported: as per notes on agenda

5.3 CRG chairs

Reported: as per notes on agenda

Considered: that publication of the CRG guide had been expected in summer 2016, and was now of particular importance since new CRGs had already been made operational. In particular, the guide promised further details on the role of CRG subgroups for particular policy proposals and clarification on this score was urgently required. Members sitting on a number of CRGs noted that little change had occurred since the initiation of the reform programme in the spring; in particular, CRGs did not yet appear to have benefitted from the improved resourcing promised by NHS England.

Agreed: that the secretariat would make enquiries on the anticipated publication date of the CRG guide and would also seek to find out more information on how NHS England proposed to support and resource the operation of the new groups.

6. SPECIALISED COMMISSIONING INTENTIONS

Reported: that NHS England's specialised commissioning intentions for 2017/18 and 2018/19 sat in the context of the strategic framework for specialised services, the Public Accounts Committee report on specialised services and the report of Lord Warner's Specialised Services Commission.

Considered: that although the strategic framework for specialised services had left open the risk that budgets and responsibility for specialised commissioning might be shared with Sustainability and Transformation Plan (STP) footprints, the specialised commissioning intentions were clear that NHS England would remain the budget holder and accountable commissioner for all specialised services in the two years ahead. This more measured approach to changes in commissioning was welcome but concerns over NHS England's transparency remained. In particular, the lack of transparency in the development of Commissioning for Quality and Innovation (CQUIN) schemes was raised along with

the need for NHS England to provide clarity on the governance and operation of STPs. Members also considered NHS England's approach to e-procurement - a consultation on which remained imminent - and how developments in this area could have a very real impact on patients, for example by limiting choice of high costs devices with insufficient clinical understanding.

Noted: that NHS England had been more ambitious in its objectives for providers to innovate in the delivery of specialised services through these commissioning intentions and it was possible that the onus for reform might pass more to the provider side.

Agreed: that while the Alliance was supportive of many overarching themes in the commissioning intentions, operational concerns remained. The Alliance would write to NHS England seeking clarity on the precise role and function of STPs in relation to specialised services.

7. PARLIAMENTARY UPDATE

7.1. PAC report

Reported: as per notes on agenda

Considered: that NHS England would need to be held to account for delivering the Public Accounts Committee's recommendations recognising that some of the associated deadlines had been unrealistic and already missed. NHS England's requirement to improve the transparency of its decision-making by publishing a document on the matter was seen as particularly important to fulfil.

Agreed: that implementation of the PAC recommendations should be part of the SHCA's future objectives.

7.2 Long-term Sustainability of the NHS Committee (Lords)

Reported: that, in addition to the notes on agenda, the committee would be focusing on five relevant topics, namely workforce, models of service delivery and integration, prevention and public engagement, and digitisation and data.

Considered: that although the committee had examined future developments in demography and life sciences, specialised services were an important aspect of the health landscape that would need to be considered, something which had been a theme of the Alliance's submission.

Noted: that a holistic analysis of the long-term sustainability of the NHS would also need to consider developments in public health and social care.

8. PRIORITISATION PROCESS

Reported: as per notes on agenda.

Considered: that there continued to be delays to the prioritisation process given legal deliberations around the commissioning of PrEP for HIV. Members expressed concern at the tone of NHS England's public pronouncements on this issue, which had seemed to pit the interests of one group of patients against another. Meetings with patient organisations affected by the process had also been promised previously but, in some cases, not yet materialised. The Director of the Alliance had contacted Jonathan Fielden at NHS England in relation to both issues and the SHCA was happy to assist any members who were still awaiting meetings with NHS England.

Noted: that these concerns had also been expressed in a letter to The Times by #patientstogether, including the Alliance as a signatory.

Agreed: that members wishing to meet with NHS England regarding the re-run of the prioritisation round could contact the Alliance's Director to help expedite this process.

9. NHS ENGLAND REGIONAL MEETINGS

Reported: as per notes on agenda

Considered: that the Alliance's report had helped shed light on initiatives currently underway at a regional level.

10. PPVAG

Reported: that, in addition to the notes on agenda, no patient organisations would now be represented on the PPVAG, with only individuals permitted to sit on the group from now on.

Considered: that the removal of patient organisations would likely hinder the PPVAG from providing genuine assurance on key NHS England decision making. Although the Alliance's longstanding relationship with NHS England would continue to allow for constructive bilateral dialogue, the diminution of the PPVAG was seen as a negative development and seemed to be counter to the interests of patients and their representatives. Members were keen to see patient organisations permitted to participate in PPVAG as 'observers' in future, as a minimum.

Agreed: that the Alliance would convey members' concerns on these developments to NHS England and the PPVAG and seek to ensure the creation of observer status to preserve external input to the PPVAG.

11. UKRDF

Reported: as per notes on agenda.

Considered: that the UK's impending exit from the European Union might dampen implementation of the UK Strategy for Rare Diseases as a product of an EU recommendation.

12. APPOINTMENT OF NEW SECRETARIAT AND 2017 WORKPLAN

12.1 Presentation on 2017 workplan

Reported: a presentation on the Alliance's activities and performance in 2016 and the anticipated policy environment in 2017 was given to members.

Considered: that there was broad support for the evaluation of the Alliance's activity in 2016 and approach for 2017. Members also commented that stakeholder engagement could be widened to include greater parliamentary and Department of Health engagement. Issues of transformational treatments and their affordability were raised in relation to the SWOT and PEST analyses given.

Noted: that the Alliance's support for patients with rare and ultra-rare conditions in the context of the prioritisation process was particularly welcome.

Agreed: that the issue of affordability was increasingly important to the prospect of patients with rare and complex conditions receiving effective treatments and should therefore be a core consideration for 2017.

12.2 New secretariat

Reported: that, further to the notes on agenda, JMC Partners' cessation of trading meant that the SHCA would need to tender for a new secretariat. To assist with this process, it was proposed to delegate responsibility to a small steering group comprising two members, two corporate supporters and the incoming and outgoing Chairs of the Alliance.

Considered: that members of the steering group should appoint the new secretariat. Simon Butler (Anthony Nolan) and Fiona Loud (BKPA) offered to sit on the steering group, representing Alliance members. Pfizer, AbbVie and Sobi had put their names forward for the two corporate supporter places. The key criteria outlined in the presentation to members were thought to be a sensible basis to inform the recruitment process.

Noted: that the current Director of the Alliance stood ready to provide background assistance to the new secretariat in the early months of 2017. Members considered it important that the incoming secretariat could

demonstrate an ethical approach, not just for its proposals in relation to the SHCA but in its wider business and client base.

Agreed: that Simon Butler and Fiona Loud would represent Alliance members, with Lord Sharkey and Baroness Wheeler taking up the office holder positions. A decision on the corporate supporter positions would be made in due course. Members agreed that the steering group would have delegated authority to assess and appoint the new secretariat, with the incoming Chair having the deciding vote in case of need.

13. REPORT ITEMS

Reported: as per the notes on agenda, unless otherwise stated.

13.1 Conflicts of interest

13.2 Meeting with Jim Mackey, NHS Improvement Chief Executive

13.3 Meeting with new Director of NHS National Services Scotland

13.4 Meeting with Colleen Fletcher, Labour MP for Coventry North East

13.5 Meeting with Lawrence Tallon, Shelford Group Managing Director

13.6 Meeting with Gareth Arthur, NHS England Head of Policy and Strategy

13.7 Letter from Lord Prior

13.8 Impact of Brexit

Reported: that, in addition to the notes on agenda, the secretariat had been tasked with preparing a report on the implications of Brexit for specialised services

Considered: that, although a report had been prepared, many of the issues related to broader NHS issues rather than specialised services in particular.

Agreed: that this report would not be circulated to members, although a careful watching brief would be maintained on matters pertaining to Brexit.

14. DATES OF NEXT MEETINGS

Reported: as per notes on agenda.

15. ANY OTHER BUSINESS

Noted: the incoming Chair wished to record the thanks of members and corporate supporters to JMC Partners for their support for the Alliance over the past 13 years.