

**MEETING OF THE SPECIALISED HEALTHCARE ALLIANCE AT 11.00 – 14.00 ON  
WEDNESDAY 11 JANUARY 2017 IN ROOM 320, 1 MILLBANK, WESTMINSTER, LONDON  
SW1P 3LX**

**Present:**

Lord Sharkey – Chair

Baroness Wheeler – Vice-Chair

Baroness Redfern – Vice-Chair

Alex Massey – Motor Neurone Disease Association

Amanda Croft - MS Trust

Andy Barrick – Multiple System Atrophy Trust

Brian Gunson – British Liver Trust

Caroline Morrice – Guillain Barre and Associated Inflammatory Neuropathies

Chico Chakravorty – The Children's Trust

Chris Sotirelis – Patient representative for thalassaemia

Christopher Hicks – National AIDS Trust

Ciaran Scott – AKU Society

Dan Betts – CSL Behring

Dan Rattigan – MS Society

Diane Splevings – Shire

Frances Luff – Gilead

Isabel Wilkinson – Teenage Cancer Trust Dr Sarah Love – Jones British Pain Society

Jeff Courtney – The Haemophilia Society

Jerome Penn – Pfizer

Miguel Souto – British Society for Rheumatology

Patrick McKenna – Together for Short Lives

Patricia Osborne – Brittle Bone Society

Richard Rogerson – Niemann-Pick UK

Sarah Hutchinson – National Voices

Dr Sarah Love – Jones British Pain Society

Simon Butler – Anthony Nolan

Steve Bojakowski - Sobi

Vicky Hargreaves – Novartis

**Secretariat:**

Bill Morgan – SHCA

Ben Nunn – SHCA

Ed McIntosh – SHCA

Elizabeth Beck – SHCA

Aalia Kazi – SHCA

## **1. APOLOGIES**

Reported: that apologies were received from the following members:

Catherine Hodder – Young Epilepsy  
Conn O'Neill – National Rheumatoid Arthritis Society  
Fiona Loud – British Kidney Patient Association  
John James – Sickle Cell Society  
Laura Szutowicz - HAE UK  
Pat Roberts – Save Babies UK  
Roger Brown – Waldenström's Macroglobulinemia UK  
Tess Harris – Polycystic Kidney Disease Charity  
Tomaz Garcez – UKPIN

## **2. MINUTES**

Agreed: the minutes of the last meeting on Wednesday 12<sup>th</sup> October 2016, which would be published on the SHCA's website.

## **3. MATTERS ARISING**

### **3.1 New Chair and Vice-Chairs**

Reported: as per notes on agenda.

### **3.2 New secretariat**

Reported: as per notes on agenda.

Noted: that the new secretariat would be happy to respond to any individual member queries. The secretariat team would be comprised of:

- Bill Morgan, Founding Partner: [Bill.morgan@Incisivehealth.com](mailto:Bill.morgan@Incisivehealth.com)
- Ben Nunn, Associate Director: [Ben.nunn@Incisivehealth.com](mailto:Ben.nunn@Incisivehealth.com)
- Ed McIntosh, Account Director: [Ed.McIntosh@incisivehealth.com](mailto:Ed.McIntosh@incisivehealth.com)
- Elizabeth Beck, Account Manager: [Elizabeth.beck@incisivehealth.com](mailto:Elizabeth.beck@incisivehealth.com)
- Aalia Kazi, Account Executive: [Aalia.kazi@Incisivehealth.com](mailto:Aalia.kazi@Incisivehealth.com)

The whole of the SHCA's secretariat could be reached on [SHCA@Incisivehealth.com](mailto:SHCA@Incisivehealth.com).

### **3.3 Membership changes**

Reported: as per notes on agenda.

#### **4. POLICY UPDATE**

##### **4.1 Personnel changes**

Reported: NHS England is continuing to try and expand its capacity given the series of changes made to the senior leadership team last year. These efforts included taking steps to increase recruitment at junior levels. However, controlling finances remained the main concern.

Bill Morgan updated the group on his meeting with John Stewart and Gareth Arthur, who was deputising for Dr Jonathan Fielden at NHS England.

Considered: NHS England is exploring increasingly sophisticated contracting arrangements for its specialised services, through a clinically-led process which increasingly focuses on delivering improvements in outcomes underpinned by robust contractual arrangements. As part of this, NHS England is exploring moves away from trust-specific contracts and towards networked, condition-focused contracts with lead providers.

Noted: that there was a move towards NHS England expanding its ability to make deals around individual treatments. For this reason, the Commercial Medicines Unit will be transferred from the Department of Health to NHS England. The work of the Unit will be to help NHS England negotiate on medicines and vaccines. NHS England would aim to develop a strategic commercial unit within, and around, the specialised commissioning directorate. Members noted that although there was ambition to do so, there was a lack of capacity. The current timeline for completing the transfer was April 2017.

##### **4.2 NHS England / NICE affordability consultation**

Reported: a strong and robust response from external stakeholders was anticipated on the consultation. The Government's support of the proposals had yet to be confirmed.

Considered: As the lack of funding and resulting 'rationing' was becoming increasingly visible, the SHCA should argue for increased funds.

Noted: that the SHCA submitted its response to the consultation in November, setting out its concerns with the proposals.

Agreed: The secretariat would draft a letter to Number 10 regarding underfunding of the NHS. The secretariat would also seek a meeting with the new Number 10 Special Advisor, Dr James Kent.

### **4.3 Scope of specialised services**

Reported: NHS England's commissioning intentions for 2017 – 2019 confirmed that it was looking for CCGs to take a greater role in the planning and commissioning of specialised services. NHS England was not looking for full accountability to be transferred but instead was aiming to enable CCGs to be more involved in designing pathways to be more responsive to local needs.

The commissioning intentions document was intended to be a road map for what NHS England planned to do over the next two years. The document included a list of 149 specialised services which were categorised by the level (national, regional, sub-regional or STP) at which NHS England considered they should be commissioned. Regardless of the level suggested, the budget would not be devolved.

More clarity on this was expected in the coming months. However, it was noted that STPs would also be expected to implement collaborative commissioning arrangements in at least the priority service areas.

### **4.4 Sustainability and Transformation Plans**

Reported: All 44 STP footprints had published a first draft of their full plan. The plans had varying levels of content in relation to specialised services and were still considered to be a "work in progress".

NHS England had been clear that these plans were not final and that there would be a period of public consultation. NHS England was also planning to publish a 5YFV delivery plan update, which is expected to be published in February or March 2017.

Although the current focus on STPs had been around cancer, it was hoped that they would also play a greater role in other service areas. It was noted that STPs had asked NHS England for help on delivering specialised services. In response, NHS England was developing a plan for specialised services and STPs.

Considered: that there was not enough evidence of patient group participation in the development of STPs. Members were also concerned about the lack of accountability.

It was also considered that it would be helpful for members to work with NHS England to support the delivery of improvements in specialised services through STPs, including through offering comments on any plan that NHS England may choose to publish.

Agreed: the secretariat would share the list of 149 specialised service areas for

members to review. The secretariat would also follow up with NHS England to confirm if the Alliance could provide support on the delivery of specialised services through STPs.

#### **4.5 Clinical Reference Groups**

Reported: that Clinical Reference Groups (CRGs) were in the process of relaunching. The chairs and lead commissioners for all but one of the CRGs had been appointed. However, the recruitment process for the full membership had yet to be completed.

NHS England had committed to announcing the full membership on its website once all the appointments were made.

Considered: there were concerns about the transparency of the CRG membership process. There were a number of questions regarding the current process for recruitment and prioritisation that members were keen to get answers to.

Noted: that the refinement of CRGs was an area of particular concern for NHS England. The prioritisation process was due to run in May, for 2017/18 and in autumn for 2018/19.

Agreed: the secretariat would prepare a list of questions for Lord Sharkey to ask on the prioritisation process and transparency.

#### **4.6 Update on the Accelerated Access Review (AAR)**

Reported: that the final report of the AAR was published in October 2016. The Government had announced that it would respond to the recommendations in its updated Strategy for UK Life Sciences, which was being developed as part of the wider Industrial Strategy.

Considered: that the Strategy for UK Life Sciences was expected to respond to wider issues around the NHS and oversight on adoption of new medicines. The Strategy is pencilled in for publication in March, although timelines may slip.

### **5. PARLIAMENTARY UPDATE**

#### **5.1 Ministerial changes**

Reported: that there had been a number of ministerial changes. Lord O'Shaughnessy was appointed to the Department of Health, where he replaced Lord Prior as Parliamentary Under Secretary of State for Health. Lord O'Shaughnessy had taken over the majority of Lord Prior's portfolio.

Considered: that it would be helpful to have a clear understanding of which aspects of his portfolio Lord Prior had taken with him.

Agreed: the secretariat would draft a letter to Lord O'Shaughnessy to congratulate him on his new role and secure a meeting. The secretariat would also share a list of responsibilities for Lord Prior and Lord O'Shaughnessy for members to review.

## **5.2 Shadow ministerial changes**

Reported: that there was a new shadow health team covering specialised commissioning, comprised of Jonathan Ashworth MP, Justin Madders MP, and Lord Hunt.

Considered: There was an opportunity for the Alliance to brief the opposition on issues, where appropriate.

## **5.3 Public Accounts Committee (PAC)**

Reported: that the Government had accepted all of the recommendations made by the Committee on its inquiry into specialised commissioning. A target of April 2017 had been set for engaging CCGs on collaborative commissioning; collecting more meaningful data; and ensuring affordability was considered when making decisions on investment.

Considered: that given concerns around transparency, the PAC intended to continue monitoring how NHS England would ensure the Specialised Commissioning Oversight Group was made more transparent. Pressure could be put on NHS England through the committee. It was also noted that PAC could provide an opportunity to hold ministers to account.

Agreed: that the secretariat would contact Meg Hillier MP in her capacity as Chair of the Public Accounts Committee.

## **5.4 Long-Term Sustainability of the NHS Committee**

Reported: that the Committee had concluded its public evidence sessions, and had taken oral evidence from a number of witnesses, including Simon Stevens and Jeremy Hunt.

Early conclusions from members of the Committee included establishing an independent body to assess NHS finances and a move towards longer-term funding settlements. The idea of an Office for Budget Responsibility style body to be created to independently assess the NHS's finances as opposed to relying solely on ministers and officials was being considered.

The Committee was expected to report back at the end of March.

Noted: that Baroness Redfern declared her interest as a member of the Long-Term Sustainability of the NHS Committee.

## **6. 2017 WORK PROGRAMME**

Reported: that the priorities for the 2017 work programme are:

- Patient involvement
- Transparency of decision making
- Consideration of rarity

Agreed: that these priorities would support the Alliance's mission in 2017.

Noted: That the SHCA was no longer a member of the Patient and Public Voice Assurance Group.

### **6.1 Meetings with key stakeholders**

Reported: A meeting for Lord Sharkey with John Stewart would be arranged as soon as possible.

Considered: that meetings with key stakeholders, DH advisors and officials, including Lord O'Shaughnessy and Dr James Kent, should form part of the work programme.

Agreed: that the Alliance would maintain meetings with key stakeholders.

### **6.2 Taking forward recommendations of the Warner Commission**

Reported: that in May 2016, an expert commission on specialised services, chaired by Lord Warner, published their final report. The report made nine recommendations on the delivery, management and cost of specialised services aimed at NHS bodies and ministers.

Agreed: that the secretariat would work with the Alliance to ensure that the report and its recommendations continued to have traction.

### **6.3 Devolution**

Reported: that the incoming Mayor of Greater Manchester would want to make the region an exemplar healthcare system and template for other devolution arrangements.

Agreed: that the secretariat would reach out to the mayoral candidates to

discuss issues related to specialised commissioning.

#### **6.4 Gathering views from the NHS frontline**

Reported: that the secretariat proposed gathering views from the NHS frontline. This would aim to provide additional support to the SHCA's public statements and reports by drawing on expertise from NHS clinicians who have an understanding of specialised commissioning.

Considered: that creating a 'sounding board' of experienced clinicians would be a helpful addition to the Alliance, in light of past discussions regarding the need for more clinical input into the Alliance's programme.

Agreed: Members and secretariat will suggest suitable clinicians for the working group.

#### **6.5 Dates of future meetings**

Reported: that it was the intention to follow the same meeting schedule as previous years, although consideration would need to be given to the Easter parliamentary break.

The future dates for meetings in 2017 would be:

- Wednesday 29 March 2017
- Wednesday 12 July 2017
- Wednesday 11 October 2017

#### **6.6 Lunch guests**

Reported: that John Stewart had agreed to be the lunch guest for the meeting on Wednesday 12 July.

Considered: that potential guests for future meetings might include Lord O'Shaughnessy, Jonathan Ashworth MP or Chairs of the PPVAG group.

### **7. MEDIA OUTREACH**

#### **8. ANY OTHER BUSINESS**

None.

#### **9. LUNCH GUEST**

Reported: as per notes on agenda.