

# Specialised Healthcare Alliance

FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS



PARLIAMENTARY EVENT – 17<sup>TH</sup> JUNE 2014

## **INTRODUCTION**

The Specialised Healthcare Alliance (SHCA) is a coalition of over 100 patient-related organisations, supported by 14 corporate members, which campaigns on behalf of people with rare and complex conditions. Further details about the Alliance can be found in Appendix 1.

In June 2014, members of the Alliance held a parliamentary day of action to raise awareness of the experiences of people with rare and complex conditions and the clinicians that help to treat them. The Alliance also launched its manifesto for specialised services, designed to inform NHS England's review into specialised commissioning and wider discussions on the future of specialised commissioning ahead of the next General Election.

The day aimed to bring together as many people with an interest in these conditions as possible, including patients, clinicians, health service leaders and a wide range of parliamentarians.

This report summarises some background information on specialised services and the Alliance's manifesto. It also outlines the day's activities and sets out some of the experiences of patients and clinicians in accessing, or providing services for rare and complex conditions.

## **CHANGES IN SPECIALISED COMMISSIONING**

### **What are specialised services?**

Specialised services are those which cannot be sensibly planned, procured and provided at a local level, typically covering a population of more than a million people. Collectively, specialised services serve hundreds of thousands of patients a year in the NHS, from the most complex neurosurgical procedures to more common services, such as renal dialysis. Patients with rare genetic disorders often need to use specialised services but specialised services are important to the population as a whole. Anyone might need to call upon specialised services at some time, for example after a serious burn or spinal injury. They currently account for about £1.4 billion of NHS spending.

### **The new system for specialised commissioning**

Specialised services are now commissioned nationally by NHS England, with no formal role for local Clinical Commissioning Groups. This aligns resource with expertise at national level and should enable NHS England to harness its power as a single national commissioner to deliver improved services for patients.

The setting of national standards, informed by clinical leadership, has been a major advance for the new system. There have also been good examples of patient and public involvement on Clinical Reference Groups and major governance committees, though lack of resource has led to sometimes patchy performance.

Under the previous commissioning system, variation in the quality of care and access to

treatments across the country was common. The new arrangements hold significant potential for specialised services, if the opportunity can be seized.

### **Challenges for specialised commissioning**

A number of significant challenges face specialised services in the months ahead.

NHS England overspent against its specialised commissioning budget by £376m in its first year of operation. In planning for 2014/15, a further overspend was projected. These deficits have been ascribed in part to the difficulties of accurately identifying historic spend on specialised services as well as weak contracting processes on the part of NHS England, susceptible to activity growth on the part of providers.

A further challenge is in integrating specialised and non-specialised care. While there is reason to believe that the new system makes sense for specialised services, a consequence has been a greater distance between nationally planned services and those planned at a local level.

Overall, early experience of the new system has brought to light shortcomings in leadership and efficiency in specialised commissioning. NHS England's Directorates were intended to work closely together in a 'matrix' approach, however, to date, siloed working and fragmented responsibilities have led to poorer performance.

### **Specialised services taskforce**

In response to the financial challenges facing NHS England, Simon Stevens established a taskforce to review the structures and processes of specialised commissioning in May 2014.

50 additional staff members have been seconded to the taskforce from elsewhere in NHS England, giving the specialised commissioning function significant extra capacity. The review comprises seven workstreams, covering financial control, structural change, clinical prioritisation and future strategy.

### **A MANIFESTO FOR SPECIALISED SERVICES**

The SHCA launched its manifesto for specialised services at the event, hoping to capitalise on the opportunities presented through changes to specialised services to ensure effective commissioning for rare and complex conditions. The Alliance is calling for:

- **Stability:** time for the new system to work before more change is introduced
- **Accountability:** NHS England leadership and accountability for specialised services through a single Directorate for specialised services with Board-level responsibility
- **Money:** urgent improvement in coding and better use of data and registries to track activity, costs and outcomes for patients
- **Integration:** integrated services to support access to tertiary expertise and care closer to home most of the time
- **Quality and Safety:** ensuring that quality and safety remain the paramount considerations in service planning, with appropriate benchmarks in place

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- **Innovation:** transparent and efficient processes and timelines for the evaluation of novel technologies, techniques and services

With stability, clear lines of accountability and an unrelenting focus on quality, NHS England will be in an excellent position to unlock the potential of the new arrangements for specialised services in the years leading up to 2020.

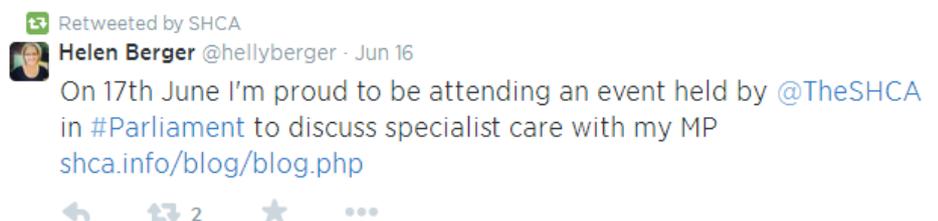
The full manifesto is included in Appendix 2.

## PATIENT AND CLINICIAN PERSPECTIVES

In arranging the parliamentary event, the Alliance was keen to ensure that the experiences of patient and clinicians would feed into discussions about the future of specialised services.

Patients and clinicians from across the country travelled to Westminster for meetings with their MPs to discuss their personal experience of specialised care. This included clinicians from NHS England's Clinical Reference Groups and patients from a wide range of rare and complex conditions, including rare inherited conditions as well as more common conditions such as Cystic Fibrosis, Multiple Sclerosis or spinal injuries.

In addition to the MP meetings, the SHCA took the opportunity to speak to patients and clinicians in attendance at the lobby to find out about their experiences.



The full list of questions that we asked are included in Appendix 3. Responses to our interview questions, as summarised below, showed clear alignment with the SHCA Manifesto.

## Stability

Patients that we spoke to emphasised their view that constant change does not enable services to establish themselves and develop organically, based on experiences to date.



Charlotte Leslie MP meeting a constituent

**“Don't change things too quickly – they will take time embedding”**

- Jayne Pye, has experience of specialised rehabilitation services

**“It's important not to change the system all the time”**

- Richard West, living with Behcet's Syndrome

## Accountability

On the issue of accountability, it was suggested that commissioning guidance might help to address concerns about who holds ultimate responsibility.

***“We need clear commissioning guidance as there is currently a great deal of confusion over which commissioning team is responsible for what task in commissioning the full care pathway”.***

- Dr Paul Monks, Consultant Psychiatrist



David Simpson MP and Jim Shannon MP in discussion with Mark and Katy Styles (centre)

## Money

While attendees recognised the importance of getting the money right, it was felt that this was an issue for NHS England. One clinician suggested that continued economic growth should prompt a reconsideration of the money set aside for healthcare.

***“Is there a point at which we will decide to invest more in the NHS? As we see economic growth we need to see some of that come back to healthcare.”***

- Anonymous

## Integration

The issue that attracted the most attention was the subject of integration. Both patients and clinicians had experienced problems with uncoordinated care, impacting negatively on the quality of care and services.

A key factor underpinning these problems was the complexity and range of services which people with rare and complex conditions have cause to call upon.

***“The pathway is not coordinated. As an example, often someone is ready to be discharged but social services have not identified a discharge destination so they have to remain in hospital. Also, patients get stuck between adult, child and adolescent mental health services and young people struggle to get into medium secure services... It is vital that services are considered as part of a coordinated network.”***

- Dr Paul Monks, Consultant Psychiatrist

***“My son is 6 years old and we access a full range of services. Coordinating his care is a significant challenge, constantly making sure that he is getting access to the best care possible. Having a key worker would really help with this. Care seems to differ depending on where you are and who you are working with, hence the need for an agreed service specification that sets out accurately the required care for all.”***

- Nick Dale, father of child with tuberous sclerosis

***“There is a tiered model of services at the core of the CRG but this is not always put into practice where services are not well developed. In particular, community services are highly variable across the country.”***

- Anonymous

***“Once we are face-to-face with the relevant service it's great but the organisation, admin and locations are a problem. We see about 21 different people. Sometimes my notes go missing and every new consultant seems to start afresh.”***

- Mark, living with Kennedy's Disease

Problems with changes in personnel and staff following the restructure were also identified as an issue:

***“In order to improve pain services, GPs need much better training as there is a real lack of awareness of where and when to refer and what can be achieved”.***

- Heather Wallace, lives with chronic pain

Retweeted by SHCA  
Andy Sawford MP @AndySawfordMP · Jun 17  
@theSHCA #speccom  
Good to meet my constituents Amanda Swain and Andrew Thomas to learn about specialist health care



## Quality and Safety

There was some comment on the ability of providers to meet the service specifications as set out by CRGs and how this should impact on whether providers continue to be commissioned to deliver a particular service.

***“Derogation will be a significant challenge for the future, i.e. making the decision that a provider should stop being commissioned to deliver a service for significant non-compliance with service specifications and quality outcome measures. An individual Operational Delivery Network does not yet have the mandate to decide this alone. Instead a Regional or Senate centred Operational Delivery Network Board consisting of patients’ representatives, specialist and local commissioners together with senior executives from each provider should facilitate and arbitrate the issues around derogation, when they are presented as part of the operational delivery networks annual reports.”***

- Dr Tim Gould, Intensive Care Consultant, Bristol

Patients highlighted some of the challenges in delivering high quality care for people with rare and complex conditions and underlined the importance of appropriate information being provided.

***“I haven’t noticed a change over the last year specifically, but over the last 4 years the service has got worse. I used to get follow-up calls. I used to have a physio as part of neuro-rehabilitation but now I don’t hear from her since the changes in occupational services.”***

- Mark, living with Kennedy's Disease

***“The NHS could provide more information to the patient.”***

- Chris Williams, born with a Bi-lateral Cleft Lip and Palate

***“The most significant problem identified with the service is related to acute episodes and the time it takes to see a specialist. I would prefer to wait and see my consultant because A&E staff do not know as much about my condition.”***

- Olivier Mmounda, living with Sickle Cell anaemia

## **Innovation**

Some people commented on a lack of research and failure to translate research into clinical practice for rare and complex conditions. There were suggestions that national action might help to address this.

***“There is lots of promising academic research but no promise to convert this into clinical use... I would tell Simon Stevens that the standard drug development model doesn’t work for rare and ultra-rare conditions and that there needs to be more centralised funding.”***

- Anonymous

***“Overall the doctors do the best they can but there is no real treatment and inadequate research and nothing is being done to address that.”***

- Jayne Bressington, Mother of child with Gastro-Intestinal Stromal Tumours (GIST)

Access to treatments, and comparisons with the old system were also raised.

***“We are currently paying for some prescriptions privately. If we had applied while PCTs existed we probably would have had access to the drugs for free...”***

***If there is a medical intervention where there is strong evidence that it works, you shouldn’t stop access on the grounds of how much it costs. This is particular true in the case of rare diseases, where lack of evidence due to lack of numbers available for clinical trial should not halt medical progress. A national prescribing policy would again ensure that all patients are treated the same”***

- Nick Dale, father of child with tuberous sclerosis

## MANIFESTO LAUNCH

Following the MP meetings, the Manifesto was officially launched at a parliamentary reception, hosted by Alison Sebeck MP.



Alison Sebeck MP welcoming attendees

Labour Shadow Health Minister, Andrew Gwynne MP spoke briefly on behalf of the Labour Shadow Health team. He recognised that the reforms to specialised commissioning were one of the stronger parts of the Health and Social Care Act and indicated that Labour would look to preserve the benefits of the current arrangements, if elected in 2015.

In particular, Andrew spoke of the need to clamp down on postcode lotteries for

patients with rare diseases. He pledged that attendees would see a supportive Shadow Health team in relation to specialised services.

Baroness Wheeler, Chair of the Specialised Healthcare Alliance, announced the launch of the Manifesto and outlined its main policy recommendations.

She described the potential of the current commissioning arrangements and the achievements to date, including the development of national specialised service specifications and the development of multidisciplinary advice – including patient voice – within Clinical Reference Groups.



Andrew Gwynne MP, Shadow Health Minister

Baroness Wheeler also spoke of the challenges facing NHS England, including the financial difficulties in the specialised commissioning budget and the need to ensure closer integration between specialised and non-specialised care.

Launching the Manifesto, Baroness Wheeler commended the six policy recommendations to attendees and looked forward to seeing the Alliance continue its engagement activities on the back of the event.



Baroness Wheeler, Chair of the Specialised Healthcare Alliance

Earl Howe, Parliamentary Under Secretary of State for Quality and the Minister with responsibility for specialised services, addressed the reception and provided the Government's perspective on specialised commissioning.

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Earl Howe, Minister with responsibility for specialised services

He began by congratulating the Alliance on its work in ensuring that patient groups have a voice in the system. Earl Howe saw it as essential that the principle that no-one should be left behind in the system, no matter how rare their condition, should be upheld.

He saw the current model for specialised commissioning as the right one and said that, if the complexities and difficulties currently observed in the system could be addressed, the system should be set fair for the future.

Echoing Baroness Wheeler, the Minister commended NHS England's work to standardise access and standards of specialised services across the country with consistent decision-making processes. On the other hand, the challenges faced by NHS England would need to be addressed in the taskforce's work.

There was a wide range of attendees at the reception, including patients, clinicians, Alliance members, parliamentarians and leading figures from across the health and social care sector.



## APPENDIX 1 - ABOUT THE SHCA

**The Specialised Healthcare Alliance (SHCA) is a coalition of over 100 patient-related organisations, supported by 14 corporate members, which campaigns on behalf of people with rare and complex conditions.**

The Alliance campaigns on overarching policies and structures within specialised care, so as to complement the work of individual members. The SHCA seeks excellent standards of care across all specialised services, supported by high quality commissioning.

**Established in 2003**, the SHCA has a strong record of campaigning for better commissioning of specialised services in the NHS. High quality specialised services are vital to people with rare and complex conditions and a frequent route for innovation.

The Alliance is **Chaired by Baroness Wheeler**, with **Lord Clement-Jones** as our Vice-Chair. They bring with them a strong record of active involvement in the House of Lords on healthcare issues.

The SHCA has been at **the forefront of developments** in specialised commissioning over the last 11 years. This has included involvement as part of the landmark **Carter Review** of specialised services in 2005/6, providing evidence to the **Health Select Committee** in 2010 and **partnership with NHS England** to help scope its future strategy for specialised services in 2013.

“The SHCA’s work to scrutinise and hold to account plans for delivering specialised services for rare and complex conditions has had an enormous positive impact for the patient population that it represents.”

**CF Trust, Cleft Lip and Palate Association, Macmillan Cancer Support, Children’s Heart Federation, Action Duchenne, Beat Eating Disorders – February 2014**

## **APPENDIX 2 - A MANIFESTO FOR SPECIALISED SERVICES – JUNE 2014**

The Specialised Healthcare Alliance (SHCA) is a coalition of over 100 patient-related organisations, supported by 14 corporate members, which campaigns on behalf of people with rare and complex conditions. Examples include severe burns, cancers, cystic fibrosis, haemophilia, HIV, much of paediatric health, neurological conditions and many more, with a total spend of more than £13 billion.

As NHS England reviews its approach to specialised commissioning and the next General Election approaches, the SHCA is calling for:

### **Stability**

The new arrangements for specialised commissioning have the potential to eliminate the postcode lottery and deliver higher standards of care to patients across England, while improving efficiency. This will however require time, making it essential to maintain stability to and through the General Election. All political parties should pledge to do so.

### **Accountability**

NHS England should show leadership to the wider NHS in the accountability it demonstrates for specialised services. This should be focused on a single Directorate with Board level responsibility for specialised commissioning. It should also include a clear description of the standards of transparency expected across NHS England's work and solid commitments to involving patients, the public and their representatives in the scope and development of specialised services.

### **Money**

The confusion surrounding NHS spending on specialised services in 2013/14 has knock-on effects for patients and must not be repeated. This requires an urgent improvement in coding and better use of data and registries to track activity, costs and outcomes for patients. The Alliance would recommend the development of a publicly available programme budgeting database for specialised services.

### **Integration**

Every specialised service should publish a network which combines ready access to tertiary expertise eg for diagnosis, with support for care in and close to people's homes the majority of the time. Integrated pathways should be predicated on universal provision of care plans, developed with patients and their families and incorporating jointly agreed use of appropriate IT.

### **Quality and Safety**

The development of specialised services should be driven by the pursuit of quality and safety for patients. This may involve reducing the number of providers but with a rationale built around patients and the improvement of clinical outcomes. The development of quality measures to monitor the performance of all services should be expedited.

### **Innovation**

NHS England needs to set out clearly how it will fulfil its statutory duty to promote innovation in relation to specialised services. This should include transparent processes and timelines for the evaluation of novel technologies, techniques and services.

With stability, clear lines of accountability and an unrelenting focus on quality, NHS England will be in an excellent position to unlock the potential of the new arrangements for specialised services in the years leading up to 2020.

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### **APPENDIX 3 – PATIENT AND CLINICIAN INTERVIEW QUESTIONS**

The questions below were used as a guide for discussion. Many of the messages for Simon Stevens were incorporated into our summary of feedback above.

#### **Patient interview questions**

1. What specialised services do you use? When were you diagnosed?
2. Overall, how would you rate your experiences of NHS care?
3. Have you experienced any changes in the care that you've received in the past year?
4. Is there anything that you would like to be improved in relation to the care that you access on the NHS?
5. You are stuck in a lift with Simon Stevens, the new Chief Executive of NHS England. What would your number one message be?

#### **Clinician interview questions**

1. What is your area of expertise? Where are you based?
2. Overall, how would you rate the services that are currently provided for your cohort of patients across England?
3. Have there been any overarching changes in the way that services are provided to these patients in the past year, as a result of changes in commissioning?
4. What are your hopes for your service area in the next five years? Do you have any concerns?
5. You are stuck in a lift with Simon Stevens, the new Chief Executive of NHS England. What would your number one message be?