

## **SHCA Conference 2013** *Seizing the Opportunities of Reform*

Report of the conference held on  
Tuesday 8<sup>th</sup> January 2013 in Westminster

The Specialised Healthcare Alliance is a coalition of 83 patient-related organisations, supported by 12 corporate members, which campaigns on behalf of people with rare and complex conditions.

**SHCA**  
**10**  
years  
2003-2013

*The **Specialised Healthcare Alliance** was formed in 2003 to improve the availability and quality of services for the many people who have rare and complex medical conditions. The following decade has seen considerable progress. In our tenth anniversary year, we look forward to continuing our work with all who have an interest in this vital part of the NHS's universal provision.*

## Contents

1. Executive Summary
2. Welcome – Baroness Jolly, Chair, Specialised Healthcare Alliance

### **OPPORTUNITIES IN SPECIALISED MEDICINE**

3. James Palmer, National Clinical Director for Specialised Services, standing in for Sir Bruce Keogh, Medical Director, NHS Commissioning Board, with Dr Diana Bilton and Dr Jackie Cornish, Chairs of Clinical Reference Groups on Cystic Fibrosis and Paediatric Medicine

### **OPPORTUNITIES FOR PATIENTS**

4. Integration - Sue McLellen, Head of Specialised Commissioning, London Region, with Sally Brearley, Chair, Specialised Services Patient and Public Engagement Steering Group
5. Diagnosis and Shared Decision Making – Catherine O’Connell, Director of Direct Commissioning, Midlands and East Region, with Dr Steven Laitner, National Right Care Shared Decision Making Programme

### **OPPORTUNITIES FOR COMMISSIONERS**

6. Policy convergence – Ann Sutton, Director of NHS Commissioning, NHS Commissioning Board
7. Innovation – James Palmer, National Clinical Director for Specialised Services, NHS Commissioning Board

### **WHO GUARDS THE GUARDIANS?**

8. Rt Hon Stephen Dorrell MP, Chair of the Health Select Committee
9. Sir David Nicholson, Chief Executive, NHS Commissioning Board

### **CONCLUDING REMARKS**

10. John Murray, Director, Specialised Healthcare Alliance

## 1. Executive Summary

In its tenth anniversary year, the Specialised Healthcare Alliance's third biennial conference brought together patient organisations, clinicians, commissioners and industry at a vital stage in the transition to the new arrangements for specialised commissioning.

NHS reform provided significant potential to see high quality specialised services available uniformly across England according to clinical need. The challenge would be to fulfil that potential, especially at a time of financial constraint.

Considerable progress had been made in preparing for the reform but much remained to be done. The final stages of transition had seen pressure on both the NHS and its key stakeholders, not least patient organisations, to ensure that specialised service specifications and policies would be robust and ready for April 2013. Further clarity would be needed on the Board's development of generic policies on IFRs, exceptional cases and resource allocation, and the scope for patient and public engagement in the new system would need to be explained more clearly. Most crucially, the levelling of service provision needed to be up not down, requiring greater efficiency.

During the course of the event:

- The National Clinical Director for Specialised Services, James Palmer, emphasised the NHS Commissioning Board's commitment to driving innovation through specialised services
- The Head of Specialised Commissioning in London, Sue McLellen, highlighted the need to concentrate on integrating specialised services with CCG-commissioned elements of care pathways, with a number of solutions which cut across therapy areas
- The role of patient organisations in helping to provide solutions to problems was noted consistently throughout the day
- The value of patients as a potential resource was noted in discussions on the application of shared decision making to diagnosis of rarer conditions
- Rt Hon Stephen Dorrell MP argued the case for politicians maintaining a close interest in the health service, standing beside the NHS to support necessary reconfigurations
- Sir David Nicholson set out the future prospects for more strategic management of specialised services under the auspices of the Board, combining the right technical structures for commissioning with the human relationships that increase its quality
- The Alliance outlined some of its focus areas for 2013, including work to ensure proper engagement in specialised commissioning and work with local and devolved organisations on the new arrangements.

## 2. Welcome – Baroness Jolly, Chair, Specialised Healthcare Alliance

Opening the Alliance's third biennial conference, Baroness Jolly welcomed the SHCA's tenth anniversary year, which would fall at a time of tremendous change in the way that specialised services were planned and commissioned. Across the lifetime of the Alliance, a number of reforms had sought to put specialised services on a better footing. The seminal Carter Report of 2006 began the process of improvement, but had been prevented from achieving all of its aims by virtue of funding continuing to rest with PCTs. The Alliance therefore looked to April 2013 with cautious hope, as the time when responsibility and resource in specialised commissioning would be brought together under the auspices of the new NHS Commissioning Board.

Baroness Jolly also reflected on the development of the Alliance over this decade. With growing influence and a steadily increasing membership, up to 83 patient-related members supported by 12 corporate members, the Alliance had maintained its core objective throughout – to seek uniformly high levels of service and access to evidence-based treatments for patients requiring specialised care.

The increasing noise around specialised services, as well as the partnerships formed with other organisations on particular issues demonstrated a vibrant and engaged environment for specialised services in 2013, with clarity on what had been achieved to date, as well as the challenges to be faced in the future.

Of these challenges, Baroness Jolly highlighted **the need for efficiencies in specialised services to ensure that standards were levelled up rather than down; the need to ensure that Clinical Reference Groups were put on to a robust footing; the need to ensure coherence in the future management of highly specialised services and the question of who guards the guardians in relation to the powerful NHS Commissioning Board.**

### OPPORTUNITIES IN SPECIALISED MEDICINE

**3. James Palmer, National Clinical Director for Specialised Services**, standing in for Sir Bruce Keogh, Medical Director, NHS Commissioning Board

James began by conveying Sir Bruce Keogh's apologies for having to withdraw from the conference at the last minute in order to meet the Secretary of State. Using Sir Bruce's slides, James reminded delegates of the progress made to date in the transition of specialised services to the new arrangements. Specialised services to be commissioned by the Board had been clearly defined as 'prescribed services', with service specifications, commissioning policies and a single operating model developed through a process of largely clinical leadership over a short transitional timescale.

The specialised services to be commissioned by the Board would be grouped under three portfolio leads – highly specialised, accounting for 7% of the budget, mental health, accounting for 19%, and acute, representing 74%. The new structures had been designed to have a clear focus on quality, with

specific pledges made at the outset to move to service availability seven days a week, with transparency in outcomes and ten pilot surgical/medical national audits to demonstrate clinical outcomes.

As the first ever National Clinical Director for Specialised Services, James outlined his ambition for the NHS to “become world class leaders in every hospital where our [specialised] services are delivered”. **He considered that ‘success’ would mean that patients were convinced that English NHS treatment represented the best in the world**, with patients in other countries seeking to travel to England for treatment, rather than English patients electing to be treated abroad. Indeed, James’ ambition was for the Board’s processes to enable companies to dispense with promotion entirely - **“with specialised services, companies don’t need to spend money on marketing, the Board will do it! Companies need to focus on getting the evidence needed.”**

Dr Diana Bilton and Dr Jackie Cornish, Chairs of the Clinical Reference Groups for Cystic Fibrosis and Paediatric Medicine respectively, followed James’ presentation with slides of their own to describe the work conducted to date by their CRGs. Both praised the work conducted through transition, including the potential of the CRGs to change the face of services across England. Dr Bilton drew particular attention to the recent innovation in gene correcting therapy for some CF patients, while Dr Cornish described the cross-cutting remit of the Paediatric Medicine CRG and the opportunities she saw to improve services. All three speakers noted the importance of their continued clinical work during transition and its significance for genuine clinical leadership through convergence.

## OPPORTUNITIES FOR PATIENTS

### 4. Integration - Sue McLellen, Head of Specialised Commissioning, London Region, with Sally Brearley, Chair, Specialised Services PPE Steering Group

Sue began by describing the programme of workshops hosted jointly by the Specialised Healthcare Alliance and each of the NHS Specialised Commissioning Group clusters through the course of 2012. The workshop held in London last summer had focused on the topic of integration as well as the wider changes in the NHS, and Sue reflected on how much the policy environment had changed, with many of the demands for further clarity which had emerged from the workshop now met or partially met.

Sue contended that **integration should chiefly be defined through patients’ experience of gaps in care. Getting it right would have the potential to improve the quality of NHS care, as well as patient satisfaction and system efficiency.**

Many specialised services operated as part of pathways, requiring seamless integration with elements of care commissioned and delivered by CCGs and others – the reforms to commissioning structures therefore provided an opportunity for improvement.

She presented the findings of the London workshop, which related to anxieties over the risk of losing expertise through transition and the need to focus on and measure the extent of integration in future. Sue argued that a great deal more

was now known about the future shape of specialised commissioning, including the identities of staff in most senior roles. While some expertise had departed from specialised services for positions elsewhere, she saw this as a potential benefit, with knowledge of specialised services becoming diffused through the rest of the health service as a result.

Sally Brearley presented selected examples of solutions for improving integration arising from the workshop. A number of common **solutions were raised across five different services, including the importance of clear signposting of care and information, the need for robust benchmarks to measure integration consistently, and the ability for staff to work with colleagues from different organisations across centre boundaries.** Sally also felt it important to note that patient organisations were keen to offer solutions which they could provide themselves, if permitted, in addition to their suggestions of further requirements of the health service.

Turning to questions from the audience, Sally emphasised that, while the move to national commissioning of specialised services was broadly to be welcomed, it would be important for the Board not to lose the regional relationships which existed in the current system. In response to a question on whether independent Foundation Trusts would be a barrier to effective integration, Sue explained that detailed discussions with providers on these issues were ongoing, with Sally adding that transparency in provider relationships would be needed to help the cause of integration.

##### **5. Diagnosis and Shared Decision Making – Catherine O’Connell, Director of Direct Commissioning, Midlands and East Region, with Dr Steven Laitner, National Right Care Shared Decision Making Programme**

Beginning with an overview of the changes in specialised commissioning, Catherine welcomed the opportunities presented by the transition to national commissioning of all specialised services. Having noted the potential of the new arrangements, however, she also noted the challenges they presented, including **the risk of fragmenting services, clinical or regional bias in Clinical Reference Groups, and resource concerns around the number of commissioners working in specialised services in future.** A further ongoing challenge would be in ensuring that patient engagement was robust in the new system, with organisations such as HealthWatch needing to reflect the views of small, dispersed patient populations using specialised services.

Dr Steven Laitner then introduced delegates to the National Right Care Shared Decision Making Programme. He defined shared decision making as a process involving patients choosing their preferred course of medical care from a range of acceptable medical options in active partnership with their clinicians. This could be seen as a ‘meeting of experts’, rather than a one-way relationship between clinician and patient. Patients had consistently expressed a desire to be more involved in decisions about their care, and recent policy initiatives sought to embed this as a routine part of NHS services, addressing variation in current provision. Steven identified three ways in which shared decision making could be embedded, with the provision of patient decision aids, ensuring shared decision making is part of NHS systems, and creating a receptive culture

for shared decision making.

Before opening the session for questions, Catherine took the chance to summarise the findings of the workshop held by the Alliance and the Midlands and East Specialised Commissioning Group on diagnosis and shared decision-making. **The key finding was that attendees had agreed on the potential for shared decision making to utilise patients' own knowledge in the context of diagnosing a rare condition.** This would necessitate a culture change for GPs, in part as a response to the inherent impracticality of gaining training on all rare conditions. Catherine emphasised the willingness of patient organisations to form part of the solution and the need to target efforts to embed shared decision making in care pathways on therapy areas with the greatest potential for improvement.

Delegates asked Steven and Catherine about the role of shared decision making in service design; Steven suggested that evidence demonstrated that greater use of shared decision making could contribute to more effectively managing services and any potential service reconfigurations. **Steven acknowledged the potential of shared decision making to contribute to more accurate diagnosis of rare diseases, and was also keen to hear from delegates their suggestions for potential topics to consider as future patient decision aids.** In response to questions on the use of shared decision-making across national borders within the UK, Catherine acknowledged that more work needed to be done to ensure that the devolved health services worked more closely together. She noted with caution, however, that the different ways in which these health services were organised might remain a barrier to fully co-ordinated services.

## OPPORTUNITIES FOR COMMISSIONERS

### 6. Policy convergence – Ann Sutton, Director of NHS Commissioning, NHS Commissioning Board

Ann Sutton introduced herself to delegates as new to her role in the NHS Commissioning Board and largely new to the specialised commissioning environment. She congratulated those involved in the transition work undertaken to date within specialised commissioning and emphasised the importance of ongoing relationships between the different core institutions – commissioners, providers, patients and other stakeholders.

She had been heartened by the earlier discussion at the conference around the importance of integration in specialised services. Ann recognised the importance of linking her role and remit for direct commissioning with the 60% of services formerly commissioned by PCTs which would pass to CCGs to commission.

On the topic of convergence within specialised services, Ann spoke highly of the Board's Operating Model, as well as the consultation on service specifications which was underway. She looked forward to the future production of developmental service specifications by the Board which, over time, would stretch and challenge providers to improve services. **The**



**convergence of policies to national standards would result in improved outcomes, transparency, and clear clinical leadership throughout specialised services.**

Alongside the convergence of specialised commissioning policies, the Board was also developing a series of generic policies. These included policies on Individual Funding Requests (IFRs), clinical trials and experimental and unproven treatments.

**7. Innovation – James Palmer, National Clinical Director for Specialised Services, NHS Commissioning Board**

James Palmer returned to the stage to address delegates on the subject of innovation in specialised services, before entering into a question and answer discussion with delegates alongside Ann Sutton.

It would be crucial to deliver a system which allowed innovation to emerge, be assessed, and roll out across the health service quickly, James emphasised. To that end, the Specialised Services Commissioning Innovation Fund was under development, along with innovation portfolios and the inclusion of innovation in national service specifications and contracts. Academic Health Science Networks might also play a role to ensure that innovation spread rapidly through to providers.

James' ambition was to address the concern raised by the British Medical Journal that innovations can take up to seven years from invention to implementation in the NHS, hoping to reduce this time lag to just a few months if the Board adopted effective policy levers. Each CRG would maintain a portfolio of innovations, including an innovation pipeline to be published at regular intervals as a form of horizon scanning in different clinical specialties. A commercial in confidence version could also be maintained to ensure that CRGs could be proactive rather than reactive in their approach to innovations.

In the plenary session, James was asked about the NHS's relationship with industry in the context of specialised commissioning. He replied that the Board was already engaging with industry on a number of fronts, and wanted to "step up" this two-way relationship. As part of this, he asked industry to change the way it behaved, asking it to work with the NHS in the new system.

Delegates also asked about the development of a generic IFR policy which Ann had announced. James confirmed that a policy was in development, and that IFRs would not represent an alternative route for routine funding in the absence of national commissioning policies – he announced that just five IFRs across the whole of England would trigger the development of a national commissioning policy, to ensure that services were developed appropriately.

A number of delegates also asked James and Ann about the short timeframe allotted for the consultation on service specifications. Ann explained that the transition work on this issue had been delayed by the late passage of the Health and Social Care Act 2012, and that the specialised services team had necessarily begun contracting discussions with providers in advance.



Returning to the theme of integration, delegates asked about the extent of interaction between CRGs and CCGs. Ann conceded that this had not yet been worked out and that the Board had first sought to have clarity on its prescribed services before turning to their relation with other services. Having said this, she also noted the first Commissioning Assembly meeting which had been held a few weeks previously, bringing CCG leaders and Board commissioners together. Adding to this, **James announced plans to pilot Pathfinder Working Groups as project groups to provide relevant CRGs with guidance to issue to CCGs on the non-specialised aspects of different care pathways.** Ann was also keen to hear advice and feedback from delegates on how integration should be managed.

Delegates asked how recruitment to the Board's Area Teams had been progressing, and whether 'derogation' from national service specifications would become the norm. Ann replied that 90% of appointments to Area Teams had been made, while James explained that derogation policy was in development, and that providers and local communities might play a role in derogation, alongside that played by the Board at a national level. Derogation was still intended to be a policy of time-limited deviation from national policies for exceptional circumstances.

On the review of CRG membership, James said he hoped that the role of patient organisations would not be weakened by the reforms due to come into effect, which he said would see separate plans for patient and public engagement and external stakeholders. Finally, he was asked whether innovations would only be considered if they were cost saving, and while he conceded that one of the drivers of innovation in specialised services was to release cash, he also recognised that innovation could not be ruled out on the basis of price, but would have to undergo clinical prioritisation.

## **WHO GUARDS THE GUARDIANS?**

### **8. Rt Hon Stephen Dorrell MP, Chair of the Health Select Committee**

Stephen began by discussing the central role of commissioning in improving services. He traced this history of this idea to the early 1990s and the introduction of the purchaser/provider split, yet reflected that commissioning for success still seemed to be an elusive concept. The reforms presented the chance to seize the opportunity of better commissioning. This was aligned with a 'burning platform in two senses', with both the tightening of financial resources and the need to improve the quality of care both adding urgency. Nonetheless, the scale of the challenge facing commissioning was demonstrated by the paediatric cardiac surgery review, which had lasted for a decade and aroused considerable controversy.

As commissioners would be charged with accelerating the pace of change, the question of 'who guards the guardians' became more important, Stephen said. In this regard, he saw a significant role for politicians. They would need to stand alongside the NHS and make the case for change to the public. In his view, they could do this while also leaving the NHS space to operate

autonomously, as in the provisions of the Health and Social Care Act 2012. **The significant sum of public money used to fund the health service meant that, no matter how autonomous the NHS, politicians could not afford to neglect their role as guardians with an interest in its performance.**

Responding to questions, Stephen urged his fellow politicians not to join picket lines and protests when changes in a local health economy became necessary. He felt that the public would understand the rationale for change if politicians stood beside the NHS in proposing it, and managers, politicians, patients and the public worked together. On the economics of the health service, Stephen acknowledged the financial pressures on the NHS, which he described as requiring 4% efficiency savings every year for the next few years, but claimed not to be as pessimistic as others in his contention that the health service could meet the challenge.

### **9. Sir David Nicholson, Chief Executive, NHS Commissioning Board**

Sir David welcomed the opportunity to address the Alliance's conference, noting in particular the good timing of the event, which fell at a key stage in the transition to the new arrangements. This was, in many respects, "the end of the beginning", and was time to stop thinking about changes and start acting to make them work.

He noted the effect of NHS jargon in dehumanising services and understating their importance. At a recent party for children with rare metabolic disorders, he was reminded of how specialised services impact the heart of families, and he encouraged delegates to keep this sense of purpose in mind in their future work.

Three to four months ago, the old system had been crumbling, but the new system had not been clear either. Now, he felt able to paint a picture of the new arrangements, and was much clearer on where improvements were needed. The Commissioning Board would have "people in every town and city" working to improve outcomes within their resource allocation.

The Board had completed its overall allocation of resources for 2013/14, which would see a 2.6% increase from baseline funding for specialised commissioning, compared to a 2% uplift for CCG-commissioned services. **This reflected the ripeness of specialised services for drawing innovation into the NHS, and Sir David was confident that the Specialised Services Commissioning Innovation Fund would play an important role in this field.**

Alongside innovation, the Board would also "need to do some really radical things in relation to service change". It would be important for the Board to hold conversations on these matters in forums such as the Alliance's conference, in seeking to focus on how to achieve "concentration and centralisation of expertise and skill" in specialised services. This would also require a change in the way the NHS approached the issue. Instead of identifying individual services to reconfigure, the Board would need to be more strategic in its approach to specialised services as a whole. Sir David was confident in the Board's capacity to achieve this, not least given its ability to

look across the board as the sole direct commissioner of these services.

Where the NHS had gone wrong in the past, Sir David said, it was when it had forgotten its purpose. The Board would “need to build a specialised commissioning capacity... which is intensely in touch with patients and the public” – building an excellent technical system, but keeping the human aspect at the forefront too.

Responding to questions, Sir David felt confident that a postcode lottery would not creep back in to specialised services. He recognised the tension in the system between local innovation and national policies, but was keen to keep the “N in NHS” through diffusion and adoption of innovations across the whole country. Delegates asked whether the Board's Area Team commissioners would be expected to engage with patients and the public – Sir David said they would be, but emphasised that specialised commissioners on Area Teams would not be “ghettoised” from the totality of the Area Teams' work either.

On the plans for implementing the findings of the Innovation Review in 2013, Sir David pointed to the emerging infrastructures of collaboration, including Academic Health Science Networks and NICE collaboratives. He also raised the development of innovation scorecards to demonstrate compliance with NICE guidance and the Specialised Services Commissioning Innovation Fund.

## **CONCLUDING REMARKS**

### **10. John Murray, Director, Specialised Healthcare Alliance**

John Murray thanked delegates for attending the conference, and welcomed the strong representation from patient organisations, clinicians, commissioners and industry. He was also keen to endorse the view given throughout the day that the best way for the Commissioning Board to command authority with CCGs was through demonstrating leadership in its direct commissioning responsibilities.

John described the Alliance as a “critical friend” to the Board. While he recognised the need for excellent structures, specialised services ultimately related to people. Sensitive services were the ultimate aim.

Within this, he referred to the Alliance's previous work on the QIPP programme. There had been, and to some extent remained, concern that focus within QIPP would be disproportionately around the productivity and prevention elements, while overlooking the quality component. If quality in specialised services was levelled down as a result of the reforms, the potential offered by the new arrangements would be lost.

He also identified softer opportunities for the Board to ensure improved outcomes in specialised services. These included the roll out of shared decision making, as had been discussed earlier in the day, and unlocking the potential of patients as a resource.

In general, there would be a number of important new interfaces within

specialised commissioning. One of the most important new interfaces would be with CCGs, ensuring seamless commissioning and pre-empting possible resentment of Board resource for specialised commissioning. The Alliance would be seeking to step up its engagement with CCGs and other local bodies over the course of the year. Another important interface would be across the borders of the English NHS, with the health services in Wales, Scotland and Northern Ireland. In the context of the UK Plan for Rare Diseases, the Alliance would also be engaging with these areas.

Earlier sessions had also flagged up the importance of the Board's generic policies, which would sit alongside those policies directly relating to individual specialised services currently being converged. It would be important to know the context in which specialised services operated, with a potential grey area developing between IFR policy and the national policy development of the CRGs. These issues would need to be considered carefully in the final months of transition.

Finally, John was encouraged that the Alliance's decision to continue championing the findings of the Carter Review seemed to be coming good. As Sir David Nicholson, James Palmer and others had all noted, the Carter recommendations continued to provide a solid basis for seizing the opportunities of reform.