REPORT OF THE
SPECIALISED SERVICES
COMMISSION

Chair: Lord Warner
# Contents

EXECUTIVE SUMMARY ............................................................................................................. 2

Recommendations: ...................................................................................................................... 4

BACKGROUND .......................................................................................................................... 6

RECENT HISTORY ...................................................................................................................... 7

DEFINING SPECIALISED SERVICES ....................................................................................... 12

NEW COMMISSIONING MODELS FOR SPECIALISED SERVICES ............................................. 17

PROVISION ............................................................................................................................... 23

PAYMENT SYSTEMS ............................................................................................................... 30

ACCOUNTABILITY ................................................................................................................... 33

DATA AND INFORMATION ........................................................................................................ 38

APPENDIX 1 – ROYAL COLLEGE OF PSYCHIATRISTS CONTRIBUTION ................................. 42

APPENDIX 2 – SPECIALISED SERVICES EXTERNAL ENGAGEMENT ..................................... 49

APPENDIX 3 – THE CHAIR AND THE SECRETARIAT ................................................................ 51

APPENDIX 4 – MEMBERS AND OBSERVERS OF THE SPECIALISED SERVICES COMMISSION .. 52

APPENDIX 5 – SPECIALISED SERVICES COMMISSION TERMS OF REFERENCE ...................... 55
EXECUTIVE SUMMARY

Specialised services are of fundamental importance to the NHS, serving people with rare and complex conditions in great need. In total, the related budget accounts for approximately £15 billion of NHS spending in England. In recent years it has grown faster than other areas of NHS spending and in total equates to more than several government departments. Specialised services also act as a vehicle for much of the innovation necessary to keep British clinical practice in the vanguard of global medicine.

Given this importance, it is perhaps surprising that the NHS’s approach to the planning and management of specialised services has been in almost constant flux. In particular, the tension between localism and specialism has been difficult to reconcile.

In 2006, a review of specialised commissioning chaired by Sir David Carter exhorted Primary Care Trusts (PCTs) to come together at regional level to pool responsibility and resource with a view to improving the consistency and quality of services. This was achieved for only half the relevant services, leading the Health and Social Care Act 2012 to move responsibility for prescribed specialised services to a single commissioner: NHS England.

These latest arrangements have helped secure funding for services which were often vulnerable at local level, and secured the development of national specifications and standards supporting improved equity of access for patients across England. In some cases, the price has been a dislocation in people’s experience of care between those parts of a pathway commissioned locally and nationally.

Against that background and given the contribution specialised services make to the major financial and demographic challenges facing the NHS, the Specialised Services Commission has sought to chart a better way forward, consistent with the principles of the Five Year Forward View. The Commission’s recommendations are also consistent with current legislation while anticipating the need for legislative change in due course.

The Commission considers that the current binary choice between local and national commissioning has often been unhelpful. It was, however, triggered by previous wide discrepancies in care which created a perhaps understandable aversion to the risks of local funding for smaller patient populations. In consequence, a broad range of services were granted prescribed, national status under the 2012 act.

In addressing this conundrum and the legitimate concern which informs it, the Commission recommends an approach to the management of specialised services founded on the principles of national standards, locally delivered. National standards will help safeguard equity for people wherever they live. Commitment to delivery at the most local level possible, commensurate with population need, will promote management and delivery closer to the patient within the available resource. It will also support a new, patient-focused, provider-
driven model of delivery for specialised services with networked care supported by robust financial and clinical governance, enabling patients to benefit from specialist oversight closer to home.

As part of this change, there is an urgent need for care co-ordinators, working across organisational boundaries, to provide a focus for patients and their needs, with individual care plans facilitating transition between specialised and non-specialised components of care. This approach to care planning and co-ordination across the entire pathway needs to be embedded in national standards and then formalised in contracts to ensure implementation. It should be combined with shared decision-making enabling patients to get the care that is right for them.

While the Health and Social Care Act 2012 remains in force, the definition of specialised services will be governed by interpretation of the four factors which determine whether a specialised service should be prescribed for commissioning at national level. Given the demanding arrangements for devolution, the Commission favours a more flexible approach to more local management based on national standards rather than formal de-prescription.

Under this model, national accountability for all specialised services would be retained, while allowing NHS England to delegate responsibility for managing different specialised services to appropriate regional and local (CCG) population levels, including combined local authorities. National management would be retained primarily for complex specialised services and highly specialised services. NHS England would be expected to demonstrate the rationale for such delegation and to account for the outcomes such commissioning arrangements deliver. Accountability vested in NHS England facilitates the development of new models for specialised services based on health economies or networks capable of providing a whole pathway service for patients, providing seamless care from the home through to tertiary centres. In particular, national standards should facilitate a greater sharing of responsibility between commissioners and providers, with the latter empowered to shape services flexibly around the needs and wishes of patients.

Primary provider and other new models for specialised care will require innovative approaches to reimbursement which move away from single institutions as fixed points of care and include a significant component for the outcomes achieved. The success of such approaches will also be dependent on NHS England demonstrating its accountability through better dissemination of performance information about specialised services and greater transparency around the involvement of providers in service development while holding them to account for outcomes thereafter.

Ultimately, confidence in specialised services and the ability to do things differently hinges on a clear understanding of what services cost and deliver. This was a primary recommendation of the Carter Report in 2006 but remains substantially unfulfilled. A clear understanding of costs and outcomes is essential in order to assess the value of specialised services and to improve prioritisation and decision-making in future. It is also fundamental to informing the
debate we need as a nation about how to match limited funding with rapidly rising demand. NHS England’s responsibility for prescribed services, supported by NICE’s approach to defining clinical standards and access to treatment, provides a unique opportunity to remedy this issue. This should also be seen as a pre-requisite for all forms of meaningful devolution of specialised services over time.

With improved data, multi-year budgets could be set as part of a long term strategy for resources, giving providers and commissioners greater certainty over their future service planning. Collaboration within this financial envelope would be a key means to maximise cost efficiency while focusing on improving care quality and patient experience. Specialised services often benefit from active and well informed patient organisations advocating for service users – the NHS will need to draw upon this knowledge systematically in developing the future specialised service landscape.

NHS specialised services have a proud record, more often than not focused on centres of clinical excellence. With the development of provider networks, there is an exciting opportunity to allay competing provider interests and support more local, co-ordinated care. Similarly, new technologies open up the prospect of the patient becoming the hub, leading to a diminished emphasis on physical infrastructure. Specialised services must be in the vanguard of this transformed approach.

**Recommendations:**

Specialised services are inevitably affected by the wider financial pressures in health and social care and need to play their part in responding to the challenge of maximising the value of every pound spent. They should expect to improve their efficiency, but the Commission recognises that improved efficiency alone is unlikely to be sufficient to avoid hard choices on what specialised services the NHS can provide over time without improved funding levels.

Against this background of financial challenge, the Commission makes the following, interconnected recommendations. The body or bodies primarily responsible for driving these recommendations are in brackets:

1. Specialised services should be defined in terms of the population level at which it makes sense to share financial risk, consistent with the best interests of patients, ensuring that services get appropriate funding to deliver best care (Ministers/NHS England)

2. The management of many specialised services should be delegated to regional and local (CCG) levels, with national management retained primarily for complex specialised services and highly specialised services (NHS England/Ministers)
3. Mandatory national standards should be retained and developed as the basis for the proposed, more innovative approach to the management and delivery of specialised care (NHS England)

4. The relationship between commissioners and providers should shift towards networks of providers being given responsibility to deliver an end to end service for patients (NHS England/NHS Improvement/Providers)

5. Contracts for networked specialised care should reflect the total cost of care for patients, thereby incentivising efficient provision in and close to people’s homes, supported by nominated care coordinators using care plans agreed with patients (NHS England/NHS Improvement)

6. Reimbursement models should be amended to reflect and encourage the development of specialised care networks, moving towards annual targeted funding for specific long term conditions, linked more closely to outcomes (NHS England/NHS Improvement)

7. Comprehensive cost and key outcomes performance data must form an integral part of these changes, for example by recognising the importance of databases in monitoring and driving performance (NHS England/NHS Improvement)

8. Where responsibility for managing services is delegated to a more local level, NHS England must be assured that data on patient outcomes and service costs will be recorded, published and used to ensure equity of service access and quality across the country (NHS England)

9. In future there should be clear-cut, annual accountability to Parliament and the public for the large sum of public money spent on specialised services, covering past performance and future priorities (Department of Health/NHS England)

In taking these recommendations forward it will be important to align with other relevant initiatives such as World Class Cancer Outcomes: A strategy for England. Similarly, this report has not sought to duplicate and should be read in conjunction with the NAO’s report on the commissioning of specialised services in the NHS and, when published, the government’s Accelerated Access Review looking at access to innovative drugs, devices and diagnostics for NHS patients.
BACKGROUND

Lord Warner convened the Specialised Services Commission in December 2015 to help inform the future development of specialised services, drawing on relevant expertise from across the healthcare sector.

Against a backdrop of rapid change in specialised services and unprecedented financial pressures across the NHS, the establishment of the Commission coincided with the 10th anniversary of the Carter Review of specialised commissioning. Sir David Carter’s 2006 report represented a significant milestone in the development of specialised commissioning and set out reforms which shape much of the debate on specialised healthcare policy today. However, unlike the more internally-focused Carter Review, the Commission has engaged with a wide range of external stakeholders, including providers, commissioners, policymakers, industry and a range of patient organisations. In doing so, the Commission has sought to develop a holistic understanding of the challenges faced in order to chart a sustainable course for the delivery of safe, high quality and efficient specialised healthcare.

Terms of Reference

In formulating this report, the Commission’s deliberations were shaped by the following patient-centred principles:

- Specialised care should be equitable, leaving no-one behind
- Patients should be assured of appropriate specialist involvement in their care
- Systems and processes should be focused on maximising patient outcomes
- Specialised care should be delivered as close to patients’ homes as possible
- Patients should be involved in decisions about their care, including future service development
- Patients and the public should be able to hold the NHS to account for the quality of specialised care.

More information about the Commission, including its full terms of reference, is provided in the appendices.
RECENT HISTORY

“Specialised services are those provided in relatively few hospitals, accessed by comparatively small numbers of patients but with catchment populations of usually more than one million. These services tend to be located in specialised hospital trusts that can recruit a team of staff with the appropriate expertise and enable them to develop their skills.”¹ – NHS England

Specialised services are a vital part of the NHS. As a comprehensive health service, committed under its Constitution to “make sure nobody is excluded, discriminated against or left behind”², the NHS must ensure that all patients receive high quality care, regardless of the rarity or complexity of a person’s condition.

In that endeavour, specialised care encompasses complex surgery, secure and forensic mental healthcare, high cost services and care for people with rare diseases. For many people, specialised services represent the last resort for treatment, or a lifeline in managing chronic but rare conditions. Any of us could have need to call upon specialised care, for example in relation to spinal injury, severe burns, or infectious diseases.

For the NHS and the wider economy, specialised services also play an important role. By their nature, they are often at the cutting edge of medical science, pioneering the use of innovative techniques or products, many of which later become standard practice across the health service. In developing the skills of the workforce, specialised care provides valuable training, and these services often have clear, mutually beneficial links with academia and research.

NHS policy on specialised services

Historically, specialised services had a low profile in the NHS. The Department of Health’s 2001 review, *Shifting the Balance of Power*³, contained only passing mention of specialised services, noting that regional collaboration beyond the scope of individual Primary Care Trusts would be necessary for some of these services.

A key turning point for the consideration of specialised services was the Carter Review of 2006⁴. This was an independent review, commissioned by Lord Warner when Minister of State for

Health, which aimed to consider the overall commissioning, performance and policy requirements of specialised services. Many of the recommendations of this review still hold good and are reflected in the Commission’s report.

In the wake of this review, regional Specialised Commissioning Groups (SCGs) were formed, providing a vehicle for pooling financial risk and specialist expertise in planning services. Further detail on these commissioning arrangements is given in the 'New Commissioning Models for Specialised Services' chapter. Importantly, Specialised Commissioning Groups were non-statutory organisations and a great proportion of specialised services were still commissioned by individual Primary Care Trusts (PCTs), or not at all.

In April 2013, the commissioning environment was radically changed by the implementation of the Health and Social Care Act 2012. Prescribed specialised services became the direct responsibility of NHS England at national level, while the majority of services were planned and managed by local Clinical Commissioning Groups (CCGs).

Under the 2012 Act, NHS England must ensure that patients across the country have access to consistent standards of specialised care. This was facilitated by the development of national service specifications and commissioning policies informed by a range of service-specific, multidisciplinary Clinical Reference Groups (CRGs).

**Funding for specialised services**

The budget originally allocated for specialised services in 2013/14 was £11.8 billion but this was rapidly revised upwards as it became apparent that data provided by PCTs had been inaccurate, activity levels grew and spending on the Cancer Drugs Fund overshot. In consequence, following the Comprehensive Spending Review in November 2015, NHS England allocated the following budget for specialised commissioning in the years ahead:

<table>
<thead>
<tr>
<th>Year</th>
<th>Budget</th>
<th>Growth</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016/17</td>
<td>£15,662m</td>
<td>+7.0%</td>
</tr>
<tr>
<td>2017/18</td>
<td>£16,413m</td>
<td>+4.8%</td>
</tr>
<tr>
<td>2018/19</td>
<td>£17,151m</td>
<td>+4.5%</td>
</tr>
<tr>
<td>2019/20</td>
<td>£17,918m</td>
<td>+4.5%</td>
</tr>
<tr>
<td>2020/21</td>
<td>£18,820m</td>
<td>+5.0%5</td>
</tr>
</tbody>
</table>

---

In comparison, growth rates for CCGs in the years ahead have been estimated at the following:

<table>
<thead>
<tr>
<th>Year</th>
<th>Budget</th>
<th>Growth</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016/17</td>
<td>£71,853m</td>
<td>+3.4%</td>
</tr>
<tr>
<td>2017/18</td>
<td>£73,358m</td>
<td>+2.1%</td>
</tr>
<tr>
<td>2018/19</td>
<td>£74,849m</td>
<td>+2.0%</td>
</tr>
<tr>
<td>2019/20</td>
<td>£76,469m</td>
<td>+2.2%</td>
</tr>
<tr>
<td>2020/21</td>
<td>£79,372m</td>
<td>+2.8%</td>
</tr>
</tbody>
</table>

Despite the growth rate for the specialised commissioning budget set at a higher level than those for CCGs in each year to 2020/21, NHS England has noted that the specialised budget remains at the lowest end of projected future demand. At the December 2015 NHS England Board meeting, Paul Baumann (NHS England Chief Financial Officer) noted that there was a significant risk that NHS England would overspend against the 7% headline specialised commissioning increase in 2016/17 as specialised commissioning faced a particular challenge in affording new “effective but expensive” drugs and devices. Furthermore, it was suggested that NHS England would potentially need to:

“Engage in further discussions with NICE and the pharmaceutical industry to reduce pressures further still, freeing up funding for other areas in 2016/17 and with a view to securing the significantly lower level of funding currently assumed for later years.”

The National Audit Office’s overview of the cost drivers facing specialised services noted rising demand, high cost drugs (accounting for around 18% of total specialised spend), and changes to the specialised commissioning portfolio as key factors.

---


9 National Audit Office, *The commissioning of specialised services in the NHS*, April 2016, p. 23
**Key challenges**

While national commissioning of specialised services has enabled the introduction of national service specifications, it has created concerns in some condition areas about a disconnect from the locally commissioned components of patient pathways.

Collaborative commissioning is now being introduced to address this disconnect. Under these arrangements, mandatory national service specifications remain in place, but NHS England collaborates with CCGs through 10 regional hubs to maximise pathway cohesion.

Substantial work has been undertaken to define the optimum population level at which different specialised services should be commissioned, although with little public output to date. NHS England and others have concluded that different services might usefully be split out to national, regional and more local levels. However, current regulations dictate a binary division of responsibility between NHS England nationally or CCGs locally.

In early 2016, the Cities and Local Government Devolution Act built upon the announcement of substantial devolution of public service responsibilities to Greater Manchester by establishing a legislative framework for such changes to take place. The legislation permits transfer orders to be put into law to enable responsibility and budget for health services to be moved from national to regional level, contingent on the agreement of all parties to such
proposals. Crucially, statutory accountability will continue to rest with the original function holder; which in the case of specialised services, is NHS England.

For specialised services, the impact of devolution remains to be seen, but Greater Manchester has begun to conduct significant work to consider how it might be able to transform the delivery of national standards in the region.

The role of specialised services within NHS England’s New Models of Care programme includes a number of specialist providers but has not yet addressed how specialised planning and provision might be placed within new care models. For example, the Mayo Clinic in the USA has employed remote working and networking to offer specialist oversight to patients living far from expert centres, enabling them to receive care closer to home.

Meanwhile, tariff arrangements for specialised services have been a constant cause of dispute between providers and NHS England as both sides of the purchaser provider split struggle to operate within available resources. This in turn creates problems for the uptake of innovation, as prioritised by the government.

In the next five years, technology has the potential to change the way that specialised services are delivered but its introduction will need to be prioritised and carefully managed.
DEFINING SPECIALISED SERVICES

Defining a service as specialised has important implications for the ways in which it is planned and managed within the NHS.

Taking into account historic changes in the scope of specialised services, the Specialised Services Commission has sought to examine how we can create a flexible delivery of specialised services, underpinned by national standards, within the current legislative framework.

Recommendations

- Specialised services should be defined in terms of the population level at which it makes sense to share financial risk, consistent with the best interests of patients, ensuring that services get appropriate funding to deliver best care (NHS England)

- The management of many specialised services should be delegated to regional and local (CCG) levels, with national management retained primarily for complex specialised services and highly specialised services (NHS England/Ministers)

Historic definitions of specialised services

Definitions of specialised services have changed markedly over the past two decades. Prior to the passing of the Health and Social Care Act 2012, specialised service were enshrined in the Specialised Services National Definitions Set (SSNDS) based on those which required a planning population of more than a million people, often correlated with less than 50 providers in England.

Changing definitions

The Health and Social Care Act 2012 enshrined a new approach to defining prescribed specialised services. This requires the Secretary of State for Health to prescribe specialised services to be commissioned directly by NHS England having regard to four factors:

- The number of individuals who require the provision of the service or facility
- The cost of providing the service or facility
- The number of persons able to provide the service or facility
The financial implications for clinical commissioning groups if they were required to arrange for the provision of the service or facility\textsuperscript{10}

**Defining highly specialised services**

The Health and Social Care Act (2012) also changed the commissioning landscape for highly specialised services. Up to that point, such services had been commissioned by a single national commissioning team on advice to Ministers from an expert advisory group; variously the National Specialised Commissioning Advisory Group, the National Commissioning Group and, from 2010, the Advisory Group on National Specialised Services (AGNSS). Highly specialised services were defined as those usually catering for fewer than 500 patients nationwide, typically with less than four providers. Importantly, highly specialised services were also seen and continue to be seen as a pan-UK issue given the small numbers involved.

The Health and Social Care Act (2012) led to the abolition of AGNSS, with advisory functions transferred to the Rare Disease Advisory Group (RDAG) and assessment responsibilities handed over to NICE. RDAG advises NHS England, NHS Scotland, NHS Wales and NHS Northern Ireland on highly specialised commissioning, making recommendations to the Clinical Priorities Advisory Group (CPAG) and receiving recommendations from NHS England’s Clinical Reference Groups (CRGs).

"Highly specialised services serve a separate distinct patient population and should not be confused with specialised services" – Niemann Pick UK

In deciding whether a service should be ‘prescribed’ as specialised, the Secretary of State for Health receives advice from the Prescribed Specialised Services Advisory Group (PSSAG), a group of expert clinicians, managers and patient representatives. PSSAG considers the following four questions as part of its decision making process:

- Whether the services currently included on the list of prescribed specialised services set out in legislation should continue to be commissioned by NHS England
- Whether there are services currently commissioned by NHS England, which would be more appropriately commissioned by CCGs
- Whether there are services currently commissioned by CCGs, which would be more appropriately commissioned by NHS England
- Whether there are innovative new treatments and interventions that are not part of existing services and which should be commissioned by NHS England\textsuperscript{11}

\textsuperscript{10} Health and Social Care Act (2012), clause 15.
As part of this process, PSSAG also considers:

- Likely running costs associated with separate and direct commissioning
- How activity can be identified to enable separate contracting, monitoring and payment
- Defining elements of service to be commissioned; and
- The number of provider contracts NHS England is likely to need to develop to directly commission the service.\(^\text{12}\)

Since the scope of national specialised commissioning was first set in April 2013, PSSAG has recommended only minor changes. In 2015 and 2016 additional services prescribed for NHS England to commission have included:

- Specialised haematology
- Primary ciliary dyskinesia
- Hand transplantation
- Maternal care (abnormally invasive placenta)
- Mitochondrial donation
- Paediatric critical care services\(^\text{13}\)

Severe and complex obesity surgery is so far the only service to have been recommended for transfer from NHS England to CCGs, with this transition staged from April 2016.

The scope of specialised commissioning

The four factors defining specialised services outlined in the Health and Social Care Act have led to significant changes in the number of services considered specialised. Under the third edition of the SSNDS (published in 2010), 34 service areas were defined as specialised. While this has undoubtedly grown, the comparison with 143 services under the Health and Social Care Act is misleading as, for example, the SSNDS did not separate out each of the more than 70 highly specialised services.

Nevertheless, a number of significant services were redefined as specialised. These were often services for relatively common conditions with a high combined cost, including radiotherapy, chemotherapy, HIV, and major trauma services.


Although many patients have benefitted from this increase in prescribed specialised services, the Health and Social Care Act introduced a sharp dichotomy between specialised commissioning at national level and non-specialised commissioning at local level, with many patient pathways straddling both. At present, there is no statutory commissioning function at regional level.

**Situation assessment**

As has been noted previously, the current scope of specialised services is broader than the previous SSNDS. With several relatively large services now commissioned at national level, there is greater likelihood of fragmentation between the specialised and non-specialised components of care pathways. As a result, there is some concern that local commissioners will have less incentive to prevent the development of specialised conditions if they are not liable for the cost.

Simon Stevens in his post-appointment hearing before the Health Select Committee in April 2014 commented:

"Part of the issue is that the way specialist commissioning was established was probably an over-extensive view of what should be defined as specialist. Some things in that category could arguably be commissioned more locally, and so one of the things we have to look at is how we do that" 14

The Health and Social Care Act allows considerable flexibility in interpreting the factors which determine whether or not a service should be prescribed for national commissioning. This could allow more services to be devolved to CCGs. Resistance to doing so, will however be greater or lesser depending on expectations of a ‘safe landing’ with local commissioners and appropriate post-transfer monitoring by NHS England in place. Crucial to this will be confidence about future funding for the services and patients concerned, which hinges on

---

sharing risk at a population level appropriate to the number of patients and the costs concerned.

It is this financial risk, which is already one of the four factors defining prescribed (specialised) services, that is most important in considering the scope of specialised services in future. At ‘local’ population levels, planning and managing expenditure on relatively high cost per capita services is difficult, and in the past often led to variable access to care for financial, rather than clinical, reasons. Local funding for specialised services is potentially iniquitous where an unusually high number of people requiring particular services might live in one area compared to a neighbouring area.

Financial risk pooling at higher population levels, underpinned by statute rather than local negotiation, must therefore be the fundamental criterion in defining a specialised service. In its purest form, this would result in a spectrum of population levels, but for simplicity a regional presence is likely to be best for the majority of specialised services. Specialist, service-specific expertise from the clinical and patient communities must be integral to any change to commissioning populations.
NEW COMMISSIONING MODELS FOR SPECIALISED SERVICES

The Commission considers that the current binary choice between local and national commissioning has often been unhelpful. It was, however, triggered by previous wide discrepancies in care which created a perhaps understandable aversion to the risks of local funding for smaller patient populations. In consequence, a broad range of services were granted prescribed, national status.

In addressing this conundrum and the legitimate concern which informs it, the Commission recommends an approach to the management of specialised services founded on the principles of national standards, locally delivered. National standards will help safeguard equity and standards for people wherever they live. Commitment to delivery at the most local level possible, commensurate with population need, will promote management and delivery closer to the patient within the available resource.

Recommendations

- Mandatory national standards should be retained and developed as the basis for the proposed, more innovative approach to the management and delivery of specialised care (NHS England)

NHS commissioning has been reformed many times since its introduction in the early 1990s. Most health reorganisations focus predominantly on changing commissioning structures, with a view to achieving more sensible planning and management of care.

In the last decade, specialised services have been the responsibility of a variety of different commissioners. There are advantages and disadvantages to any commissioning model. The Commission has assessed each of those used in recent years and, recognising their various strengths, considered the optimal model for the future, consistent with current legislation.
<table>
<thead>
<tr>
<th>Commissioning structure</th>
<th>Advantages</th>
<th>Disadvantages</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local commissioning of specialised services – Primary Care Trusts</td>
<td>PCTs’ frontline role meant that they had particular expertise in commissioning. Furthermore, this commissioning typically applied to the entire pathway and involved close collaboration with providers.</td>
<td>Smaller patient populations can easily be overlooked and be deprived of investment, especially where costs are relatively high</td>
<td>“Worryingly, the evidence which we received indicates that many PCTs are still disengaged from specialised commissioning. Furthermore, there is a danger that the low priority many PCTs give to it will mean that funding for specialised commissioning will be disproportionately cut in the coming period of financial restraint.” - Health Select Committee, Report on Commissioning (2010)</td>
</tr>
<tr>
<td>Regional commissioning of some specialised services – Specialised Commissioning Groups</td>
<td>Smaller patient populations catered to effectively through PCT resource pooling. Commissioning expertise is also brought together through SCGs, thereby allowing for more effective commissioning.</td>
<td>SCGs were never on statutory footing and were always dependent on their constituent PCTs, thereby curtailing their effectiveness in commissioning services to meet specialised patient need.</td>
<td>“We were informed that SCGs had no authority over PCTs, since the former were actually sub-committees of the latter. This means that SCGs have no power to oblige PCTs to participate in collective commissioning, or to make them commission services locally when they are not commissioned at the regional level” - Health Select Committee,</td>
</tr>
</tbody>
</table>
A new settlement for specialised commissioning

Taking on board the lessons of the past, the Commission recommends that specialised services should be founded on the principle of national standards, locally delivered. Under this principle, the commissioning of specialised services would not favour those living in a particular geographical area, nor would it allow a significant disconnect between local and national commissioning. Instead, by allowing for local management and provision of specialised services under the auspices of national standards, greater integration could be facilitated, while preserving equity. Moreover, retaining national standards will allow attention to move to how providers and others can focus on improving specialised care delivery, supported by commissioners rather than held back by commissioning.

"Without defined national standards, there is a risk of fragmentation of services and increased variability in quality and scope of specialist services by geographical provision" – Royal College of Physicians of Edinburgh
These standards should continue to set out the mandatory requirements for patient access to services and the quality of those services in England. They should describe the core elements of a service, for example the minimum requirements for the composition of a specialist multidisciplinary team, as well as other essential features of a service including the Commission’s desire to see mandatory care co-ordination. Ideally, service specifications should also set expectations for patient outcomes. The management and delivery of these core standards should then be a matter for local providers working alongside appropriate commissioners for strategic direction.

Greater Manchester – devolving specialised commissioning

Greater Manchester devolution represents the most significant change currently being undertaken for the planning and management of specialised services. Here, a new settlement for provider and commissioner collaboration and regional innovation in the context of national standards is already being explored in earnest.

The current drive towards greater collaboration across the region has frequently been emphasised by Sir Howard Bernstein, Manchester City Council Chief Executive. Reporting to the NHS England Board in March 2016, Sir Howard stated that regional collaboration between commissioners and providers could improve “information sharing and information governance”, and facilitate the development of “a radical payment innovation and contracting mechanism to align incentives in a reformed system”, all of which is pertinent to the future of specialised services.

Through work spearheaded by NHS Trafford CCG, specialised services across the region have been analysed and stratified into commissioning level tiers. With national specifications preserving core standards for services, this has meant that an innovative and collaborative approach to specialised commissioning redesign has been facilitated, potentially providing a direction of travel for the future of specialised services elsewhere in the country.
The role of national service specifications

National specifications for specialised services were newly introduced in April 2013 – they have since become a core feature of these services.

“*A national consistent and coherent approach to specialised commissioning has been developed which builds on universal support... A consistent approach to central planning that is delivered locally will help tackle these variations and take positive steps towards raising standards of care for all patients receiving treatment for rare and specialised conditions with equity across the country.*” – *NHS England, first operating model for national specialised commissioning, 2012*

The main advantages of national specifications are:

1) The ability to reflect best practice at national level, informed by specialist expertise pooled from across the country

2) The equity delivered by uniform service and access standards in place across England as a whole, where previously a postcode lottery had been experienced and specialised services had been vulnerable to local deprioritisation

3) The liberation of local areas and providers to innovate in the delivery of these core standards for patients, putting the onus on provider leadership and service improvement rather than the development and revision of local service specifications.

The Commission agrees with the written submissions received during its call for evidence that mandatory national service specifications remain a vital part of the future of specialised healthcare and are key to delivering improvements in the years ahead.
Case study: a more flexible approach to specialised commissioning for cancer

Cancer accounts for the largest single therapy area spend within the specialised services budget.

In July 2015 an Independent Cancer Taskforce published a new strategy for cancer. This was based on wide engagement with the clinical community, commissioners, charities and patients.

Part of this report included an attempt to define the levels at which different cancer services should be commissioned and some models and enablers of effective provision. Of most relevance to the Commission are:

**Populations and responsibilities**

In order to create better coherence in cancer commissioning, recognising the need for specialist expertise and capacity where appropriate, the Independent Cancer Taskforce recommended the following arrangements for cancer commissioning.

![Figure 23: Proposed commissioning of cancer services](image)

In addition to these population groups it is important to recognise the need for specialist expertise and services for consequences of treatment. This fits within the 4-5 million bracket.

**Provision**

Using these populations as the basis of commissioning, the Independent Cancer Taskforce also explored potential ways for providing care. This included a recommendation that Monitor (now NHS Improvement) should work with NHS England to pilot whole population and whole pathway commissioning.
The Commission would favour a new, patient-focused, provider-driven model of delivery for specialised services, with networked care supported by robust financial and clinical governance, enabling patients to benefit from specialist oversight closer to home.

Care co-ordinators would play a fundamental role in this new landscape, working across organisational boundaries. They would focus on patients’ needs with individual care plans facilitating the transitions between specialised and non-specialised components of care. To ensure that such an approach is delivered on, it should be formalised in contracts with providers, along with shared decision-making to ensure patients get the care that is right for them.

**Recommendations**

- The relationship between commissioners and providers should shift towards networks of providers being given responsibility to deliver an end to end service for patients (NHS England/NHS Improvement/Providers)
- Contracts for networked specialised care should reflect the total cost of care for patients, thereby incentivising efficient provision in and close to people’s homes, supported by nominated care coordinators using care plans agreed with patients (NHS England/NHS Improvement)

**Concentration of specialised services**

The need for a sufficient volume of patients to develop and sustain clinical expertise and outcomes is well recognised and applies with particular force to specialised services with relatively small patient numbers. This is supported by NHS England’s Manual for Prescribed Specialised Services:

“A critical mass of patients is needed in each treatment centre to achieve the best outcomes and maintain the critical competence of clinical staff. Concentrating services in this way ensures that specialist staff can be more easily recruited and their training maintained.”
"It is also more cost-effective and makes the best use of resources such as high tech equipment and staff expertise."\textsuperscript{15}

The positive correlation between volume and outcomes has favoured greater concentration of specialised care. Until recently, this became conflated with the size of providers. For example, NHS England’s planning guidance for 2014/15 to 2018/19, titled \textit{Everyone Counts}, pledged the NHS to work towards concentrating the delivery of specialised services in a smaller number of centres:

“The Through NHS England's direct commissioning we shall be looking to reduce significantly the number of centres providing NHS specialised services, requiring standards of care to be applied consistently across England and maximise synergy from research and learning.”

“...we can foresee a concentration of expertise in some 15 to 30 centres for most aspects of specialised care.”\textsuperscript{16}

Concerns were raised about the practicality of such a wholesale reorganisation of specialised services, which paid little heed to concentration in smaller, specialist providers and the need to balance concentration with considerations of geographical access.

Furthermore, attempts to reconfigure specialised care provision have typically met competing provider interests, political interventions and regulatory barriers preventing service change. Challenges such as these, have historically stymied progress towards specialised services consolidation. Since the establishment of NHS England, by describing the mandatory elements of a service, national service specifications have been a means of ensuring the concentration of specialised care at centres capable of delivering the best outcomes, consistent with competition law. This provides an additional reason for the Commission’s recommendation.

\textbf{New models of care delivery}

The Chief Executive of NHS England Simon Stevens recognised the challenges associated with reconfiguration and, instead, advocated a more flexible approach towards the future of provision. In his first speech to the NHS Confederation Annual Conference as Chief Executive in 2014, Stevens said:


“In some places mergers and traditional reconfigurations will – after careful stress-testing – clearly be needed, and they will have NHS England’s full support.”

“But let’s also allow complementary models to emerge, be tested, and adapt over time, in different communities, reflecting their different legacy care patterns and the heterogeneity of their patients.” 17

This is consistent with the Five Year Forward View’s recommendations on specialised care:

“In services where the relationship between quality and patient volumes is this strong, NHS England will now work with local partners to drive consolidation through a programme of three-year rolling reviews. We will also look to these specialised providers to develop networks of services over a geography, integrating different organisations and services around patients....” 18

The Forward View identifies an alternate solution to the problem of scale. Historically, the assumption has been that there was a binary choice between quality and accessibility. In order to achieve the highest quality care, organisations needed to have ‘critical mass’, achieved through the concentration of specialised services in a small number of very large tertiary centres. But, given the geographical distribution of these centres, reconfiguration would often make services less accessible for some patients.

In contrast, a networked approach to care delivery offers a potential solution to the dichotomy between quality and accessibility. By establishing links between tertiary and community-based care, specialised care networks allow organisations to pool their resources and patient populations together to achieve critical mass and improved quality, while enabling patients to benefit from specialist oversight closer to home. New technologies also open up the prospect of the patient becoming the hub with a declining emphasis on physical infrastructure. In doing so, these networks facilitate the very best care delivered locally, in a way that is most convenient and accessible for the patient.

Specialised care networks

Whilst the Forward View makes significant headway in describing the model of provision which is best placed to drive improvements in specialised care, the main challenge continues to lie with implementation.

“The landscape should allow for the better alignment and integration of social care, CCGs and providers” – Royal College of Psychiatrists

A number of recent reports have helped to translate the ideas of the Forward View into reality, not least of which is the Dalton Review into future organisational models for the NHS. Those with particular relevance to specialised care include:

- **Clinical networks** – clinical networks have been used by clinicians to develop and share best practice in the NHS for a significant time. Using these partnerships, trusts are able to establish wider referral networks and work together to create seamless patient pathways for the services they deliver. These networks have been formalised by NHS England in the form of Strategic Clinical Networks, tasked with improving patient outcomes in areas such as cancer, heart disease, dementia and neurological conditions.

  "Specialised service models are more effective if collaborative, integrated working between providers is encouraged and supported both clinically and financially" – *Royal College of Physicians of Edinburgh*

- **Service level chains** – one provider may be asked to deliver a service or specialty from the premises owned by another provider. This is what is often described as the ‘at’ or @ model, and could be considered as a local provider ‘outsourcing’ their activity. Arrangements such as this require that the service provider has the necessary expertise and capacity to run services in distant sites on a day-to-day basis. When delivered successfully, they enable the delivery of more local care to patients where possible with specialist oversight where necessary.

  "Novel and successful approaches to the provision of specialised care need to be shared between providers" – *Royal College of Radiologists*

- **Accountable care organisations (ACO)** – a lead provider or a group of providers may be commissioned to deliver a service or specialty. The lead provider may then issue sub-contracts to other providers, managing patients from a particular population across defined care pathways supported by shared data, IT and information systems. The ACO usually work under a contract agreed with commissioners who will define the outcomes the ACO will be expected to deliver.

  "It is essential to have provider expertise in all aspects of management and specialist service development" – *British Society for Paediatric Endocrinology and Diabetes*
Whilst each of these organisational forms could be broadly described as a specialised care network, they have vastly different characteristics, benefits and barriers to implementation. It is clear that no single organisational form can suit all specialised services and each of the approaches will need to be tested and adapted over time to suit the specific needs of the local patient population. In this regard, the Commission endorses Sir David Dalton’s view that:

“There are no ‘right’ or ‘wrong’ organisational forms – what matters is what works. ...it is for our system leaders to pursue the models that will deliver the greatest benefits to the populations they serve.” 19

**Considerations for networked care**

As part of the Forward View’s effort to transform models of provision, NHS England, the Department of Health and its arms’ length bodies are working with vanguard sites around the country to trial and evaluate new ways of delivering care.

For specialised services in particular, 13 hospital vanguards have been chosen to take part in the ‘acute care collaboration’ element of the programme, with a view to supporting improvements in services with low patient volumes while maintaining local access for patients and their families.

The following section sets out some factors that organisations should consider as they implement the Forward View’s vision for specialised care delivery.

**Integration**

Too often under the current system of specialised care, there is a fragmentation of care with patients having to visit multiple professionals for multiple appointments in both primary and specialised settings, endlessly repeating their details because organisations use separate paper records. There is broad consensus that the future model of care should support the whole person, wherever they are being treated, not single diseases or aspects of their condition. Just as there is a consensus that far more care should be delivered locally but with some services in specialist centres where that clearly produces better results.

The mere establishment of a specialised care network is insufficient to resolve the issue of fragmentation fully. Experience shows that services that operate more efficiently tend to be those that coordinate between the different elements of care and pre-empt problems that are likely to trigger an escalation of requirements, whether that be an emergency admission to hospital or an unnecessary deterioration of someone’s condition. Making sure that people

---

can access appropriate advice and support in a timely manner improves patient experience and enables a more effective use of resources.

The Commission believes that there is an urgent need for care co-ordinators, working across organisational boundaries, to focus on patients’ needs with individual care plans facilitating the transition between specialised and non-specialised components of care. Care plans and care coordinators are, however, the hardy perennial of policy reports with limited implementation to date. To ensure that such an approach is delivered, it should therefore be formalised in contracts with providers, along with shared decision-making to ensure patients get the care which is right for them.

As noted elsewhere in this report, it is of paramount importance that the outcomes achieved, whether through provider leadership in networks or from commissioner service management must be measured and accounted for.

**Clinical standards**

As specialised care networks expand, there is a challenge of maintaining clinical expertise and outcomes across multiple, geographically discrete organisations.

Networks should be set up to ensure that a critical mass of patients is available across the partner organisations. They should be configured to enable local hospitals and other providers to gain the benefits of scale, whilst ensuring ready access to tertiary expertise when required.

In addition, transparency of clinical data is important so that each partner organisation is held to account for continuously improving outcomes. This should be supported by standardised network protocols and pathways, backed by national service specifications and best practice in order to safeguard the quality of care delivered.

**Commissioning relationships**

Establishing a specialised care network, may currently trigger the need to for complex sharing of responsibility and budgets for particular services across organisations. The process is far from simple and likely to involve protracted negotiations between commissioners and the range of providers delivering the service, who may be incentivised to maximise their income rather than optimise the efficiency of the service for patients. Commissioner support for the network is therefore crucial but may not be sufficient to an effective network.

There would seem to be significant advantage in directly commissioning a single provider or a provider group to run the networked service rather than contracting across a number of organisations. This can help to streamline communication, reduce transaction costs and ensure that data is held on consistent systems and formats. A single contract should also help integrate services across the needs of patients, without having to navigate across multiple organisational boundaries.
In delivering seamless patient care such arrangements would also facilitate financial flows from the primary to other providers involved in the care of a patient, for example from tertiary to primary care.

**Delivering high quality specialised mental healthcare**

Similar networking considerations apply to specialised mental healthcare, which has been affected significantly by the introduction of national commissioning arrangements. At the Commission’s request, the Royal College of Psychiatrists has prepared an appendix to this report to describe these developments in greater detail and to consider the future direction of policy for specialised mental health services. The Commission’s recommendations as a whole are intended to be applicable to the breadth of specialised care, including mental and physical health.
PAYMENT SYSTEMS

As the planning, management and delivery of specialised care evolves during the years ahead, the payment system which governs reimbursement across the system will need to undergo similar change.

The Commission has considered the role that payment system reform could play in improving outcomes from specialised services.

**Recommendation**

- Reimbursement models should be amended to reflect and encourage the development of specialised care networks, moving towards annual targeted funding for specific long term conditions, linked more closely to outcomes (NHS England/NHS Improvement)

Although their primary function is to reimburse providers for the cost of treating patients, payment systems are also one of a small number of mechanisms which can support distinct health objectives.

**National Tariff**

With the Commission recommending a series of changes to the overall provider landscape, it is important to ensure that payment systems adequately align with new models of provision. Without an examination of payment systems within specialised services, there is a danger that care integration - particularly through accountable care organisations and lead provider models - will suffer due to a lack of financial incentive.

“Payment systems can influence costs, quality and volumes of care. Although evidence would suggest that the magnitude of their impact may often be small” – Health Foundation

Under current payment arrangements for many specialised services, incentives do not align with the need for integrated care. Though the majority of specialised service costs are covered by prices agreed locally between providers and commissioners, Payment by Results still accounts for around one third of specialised service reimbursement.
The National Tariff is widely seen as incentivising hospital-based activity. Ben Gershlick and Anita Charlesworth have pointed out that the National Tariff works effectively when an episode of care has a distinct start and end point, and when care can be adequately planned in advance.\textsuperscript{20} Furthermore, the National Tariff has in the past acted as an effective remedy to under-servicing and provider inertia.

However, despite these manifest strengths, particularly with regard to acute care activity, it is not a system that aligns well with the probable future evolution of the specialised provider landscape. For instance, under the accountable care organisation model or lead provider model, the National Tariff militates against care being shared between a number of relevant providers. Instead, it can provide an incentive for centralised treatment, greater fragmentation and sub-optimal quality.

Consequently, in order to complement changes within the provider landscape, it is important to examine how changes can be made to the current payment system.

**Options for change**

The varied nature of specialised services naturally means that a ‘one size fits all’ system cannot be implemented. Changes to reimbursement arrangements within specialised services must instead bear in mind the unique requirements of conditions that have been prescribed as specialised.

However, for specialised services currently covered by the National Tariff, a capitated approach may best complement and enhance changes to the provider landscape. Under a capitated system, providers are paid prospectively for each patient treated. This payment covers a number of pre-specified services agreed between the commissioner of activity and the provider. Under a capitated system, money still follows the patient, thus incentivising overall care quality.

Despite its potential, the impact of payment system reform must not be overestimated. Marshall notes that “while the payment system is important, the evidence suggests that reform will take a long time and the effect of any changes is likely to be modest and highly dependent on other changes.”\textsuperscript{21}

\textsuperscript{20} Gershlick and Charlesworth (2015), \textit{Written submission to the Specialised Services Commission}, p. 4.
Nevertheless, payment system reform has a significant role to play within specialised services, especially at a time of financial challenge. It is therefore vital to chart the future direction for payment systems, highlighting both the need for a varied and flexible approach suited to the diversity of specialised services, along with overall financial and operational stability. It would seem particularly important to grant greater clarity through multi-year budgeting as the basis of any future payment system reform, given the scale of the service changes required.

Looking ahead

The Commission would see great benefit in moving towards multi-year budgeting and, alongside this, multi-year tariffs to give the system greater stability to plan for the future.

The payment system should be refined in the years ahead to reflect the changes in provision which the Commission wishes to see, with networks explicitly catered for and incentivised within tariff.

ACCOUNTABILITY

The geographically dispersed nature of specialised care and the isolation frequently felt by people with rare diseases makes clear lines of accountability for patients and the public all the more important. Similarly, the high cost of many specialised services makes it important to ensure that associated public money is well spent.

The Commission considers that more could be done to improve the accountability, in practice and perception, of NHS England for its decisions as the sole commissioner of specialised services. Moreover, across the system as a whole, mechanisms for holding providers and others to account for the quality of specialised services could be enhanced.

Recommendations

- Where responsibility for managing services is delegated to a more local level, NHS England must be assured that data on patient outcomes and service costs will be recorded, published and used to ensure equity of service access and quality across the country (NHS England).

- In future there should be clear-cut annual accountability to Parliament and the public for the large sum of public money spent on specialised services, covering past performance and future priorities (Department of Health/NHS England).

Specialised services account for almost £15billion of NHS spending – this is more than the total spend of many government departments. It is clearly in the public interest to ensure that the associated decision-makers are well measured, assessed and held to account.

Responsibility for specialised services is relatively unique in being under the direct control of NHS England. It should therefore be clear to patients and the public how its decisions are discharged and how accountability is put into effect.

From the patient perspective, it will also be important to ensure that providers and others can be held to account for the quality of specialised care they deliver. This is more complicated but nevertheless vital to clarify in order to strengthen the delivery and continuous improvement of specialised services, especially if providers are given an enhanced role in driving change.
There is no substitute for co-production and engagement with patients and their representatives in developing better policy and delivering better services. Robust mechanisms to engage with patient organisations and co-produced key service documents will be vital to the future success of specialised services, and the demonstration of proper accountability to patients.

These matters are of particular importance at the present time. With moves towards greater collaboration between specialised commissioners and others, as well as the ongoing devolution of responsibilities for some aspects of specialised commissioning to Greater Manchester and elsewhere, maintaining and improving clarity on how accountability is managed throughout the system will be key.

**NHS ENGLAND’S ACCOUNTABILITY**

**Decision-making accountability**

At present, there are a number of ways in which NHS England can be held accountable for decisions made concerning specialised services commissioning.

**Accountability to Government: the Mandate**

The Mandate to NHS England is the Government’s principal method in assuring overall NHS accountability. The Mandate, in outlining broad health objectives, helps ensure that the NHS is accountable to the Secretary of State. The Health and Social Care Act outlines the ways in which the Health Secretary must assess NHS England’s performance in broad terms.22

> “There continues to be a need for increased accountability for services that are directly commissioned by NHS England” – Teenage Cancer Trust

As such, the Mandate is relatively broad-brush, focusing on overarching health objectives. Specialised commissioning, despite representing NHS England’s largest area of direct spending, is not mentioned in the Mandate. Previous Mandates have only specified a general duty to hold NHS England account for the quality of its direct commissioning or, for 2016/17, measuring its “national health outcomes”.23

---


Although the Mandate has the potential to become a strong tool in holding NHS England to account for decisions made on specialised services, the objectives set out in recent years have lacked the rigour and precision required for this to become a reality.

Furthermore, the Department’s ability to hold NHS England to account, for example through its regular accountability meetings, has arguably been compromised by the still growing gulf in resources available between the two organisations.

**Accountability to Parliament**

Parliament is also in possession of several mechanisms by which to discharge accountability. NHS England can be held to account by the Health Select Committee, the Public Accounts Committee and the National Audit Office, all of which are able critically to examine relevant issues in specialised services.

"In practical terms, the buck should stop with the provider if it relates to service provision, and the commissioner if it relates to commissioning. A transparent framework for accountability should be jointly developed“ – Royal College of Psychiatrists

The National Audit Office’s (NAO) new report on specialised commissioning enables the Public Accounts Committee to exercise parliamentary scrutiny. As stated by the NAO, “part of our role is to report to Parliament on the value for money obtained by government departments and other public bodies”.24 In considering the report, the Public Accounts Committee will seek to examine whether NHS England has been “delivering value for money in the commissioning of specialised services.”25 While the Committee’s hearings, deliberations and report will represent accountability in action, such proceedings are undertaken on an ad hoc basis and are not a routine part of the system. This is also the case for the Health Select Committee, which has not examined specialised services since its overarching report on NHS Commissioning in 2010.

**NHS England assurance**

NHS England is also able to demonstrate its accountability to patients and the public by assuring itself on its activities.


The Patient and Public Voice Assurance Group (PPVAG) aims to provide external assurance for NHS England’s commissioning decisions. As stated by NHS England, the PPVAG aims to “help NHS England put the patient and carer perspective at the heart of commissioning, offering constructive challenge where necessary.” However, the group fulfils a relatively limited function relating to process assurance, rather than holding NHS England to account for its decisions.

NHS England also seeks assurance via consultation on proposed new policies and specifications within specialised commissioning. These increase the legitimacy of the associated decisions if NHS England can demonstrate stakeholder support for its policies, or provide evidence that public concerns have been taken into account.

More broadly, patients and their representatives can bring further expertise, insight and capacity to bear on the challenges facing their services. The Richmond Group of charities recently outlined the many ways in which the voluntary sector can add value to health and social care, and these lessons are of particular importance for more complex services.

**Transparency**

Transparency plays a vital role in ensuring that decision-makers can be held to account for their decisions. The Government has stated that it is committed to transparent governance, with the Prime Minister commenting that “information is power…it lets people hold the powerful to account, giving them the tools they need to take on politicians and bureaucrats.”

To date, the transparency of NHS England’s specialised commissioning function could be improved. NHS England has not published the minutes of its specialised commissioning committees, hindering public accountability for decision-making. The Clinical Priorities Advisory Group (CPAG), the Specialised Commissioning Oversight Group (SCOG) and the Specialised Services Commissioning Committee have not published minutes and the Patient and Public Voice Assurance Group has only published minutes from June 2014 to April 2015.


Furthermore, although NHS England stated that CPAG would publish “meeting minutes on the NHS England website” and would be “open to public scrutiny and...publicly accountable” this has yet to occur.29

This relative lack of transparency hampers the ability for the decisions taken to be adequately scrutinised and for NHS England as a whole to be held accountable.

ACCOUNTABILITY FOR THE QUALITY OF SPECIALISED CARE

Alongside accountability for NHS England’s decision making, it is vital to examine how providers can be held to account for the quality of specialised service delivery.

Accountability to commissioners

Providers can be held to account by NHS England as the national commissioner of specialised services. NHS England is able to assure delivery against specialised commissioning contracts and, where necessary, apply a time-limited exemption, or derogation, from national service standards to allow time for a provider to become compliant.

Accountability to regulators

Providers can also be held to account by healthcare regulators. The Care Quality Commission (CQC), for example, has a remit to inspect NHS providers. However, these are general initiatives for provider improvement, rather than programmes focused on assuring the quality of specialised care.

Looking ahead, one option might be to formally task the CQC with responsibility for inspecting specialised care as a core service for those providers with a major specialised service portfolio.

Local accountability

Hospitals are also accountable to their Boards and to their Councils of Governors and members for their clinical and financial performance.

RETAINING ACCOUNTABILITY IN A CHANGING ENVIRONMENT

As the commissioning and delivery of specialised services develops and evolves in the years ahead, it is absolutely vital that patients and the public are able to hold decision-makers to account within specialised services, and are able to have clear sight of accountability for service quality.

DATA AND INFORMATION

Throughout its deliberations, the Commission has been struck repeatedly by the urgent need for improvements in the collection, analysis and application of data within specialised services.

Indeed, the full benefits of the Commission’s recommendations cannot be met without significant improvements in respect of data and information going forward.

This chapter elucidates the case for improved standards, drawing on real-world examples where data has helped drive greater care quality and efficiency.

Recommendation

- Comprehensive cost and key outcomes performance data must form an integral part of these changes, for example by recognising the importance of databases in monitoring and driving performance (NHS England/NHS Improvement)

HOW BETTER DATA UNDERPINS THE COMMISSION’S RECOMMENDATIONS

Data on costs

The Carter Review recommended in 2006 that all specialised care pathways should be fully costed. This has still not happened. Furthermore, the data available for highly specialised services has tended to deteriorate as budget holding has been dispersed from a single national team to NHS England’s regions. The improvement of data is essential to most if not all the Commission’s recommendations and therefore needs to be prioritised.

In April 2016, NHS England published a report, agreed with the Advisory Committee on Resource Allocation, with an unprecedented breakdown of the specialised service budget mapped against Clinical Commissioning Group boundaries. The paper examined utilisation of specialised services within local areas, which stood at 2-4%, as well as providing an exploration of the difficulties inherent in assembling data on specialised activity. The paper’s main data source was 2013/14 SUS PbR data, which was then adjusted for identification rule changes, but the gaps in this data were also noted. When considering whether person-based resource
allocation could be used, the report noted that data would only be available for 30% of specialised spend.\textsuperscript{30}

This paper is perhaps most helpful for demonstrating the possibilities of data analysis within specialised commissioning, given that, for the most part, the report considered the accuracy of the data to be solid. The report hints at a practical application for this analysis, in noting the differences between spending levels for different Programmes of Care. However, only the figures for ‘digestion, renal and hepatobiliary and circulatory system’ and ‘infection, cancer, immunity and haematology’ are given, representing 42% and 25% of specialised inpatient spend respectively.\textsuperscript{31}

The Commission commends the good work demonstrated by NHS England’s financial analytics team but is concerned that robust spending information remains elusive for individual services. This is vital to good payment systems, the improvement of efficiency and an essential pre-requisite as and when CCGs are asked to assume responsibility for particular specialised services as a function of devolution.

"Seamless communication is an essential aspect of specialist services. This requires shared clinical data and so investment in databases" – BSPED

Data on outcomes

Outcomes data is collected across the NHS but efforts have tended to focus on priority areas specified by the Government via the NHS Mandate. The Commission considers that there is great potential to expand the collection and application of outcomes data across specialised services. Providers are providing information about the specialised services they deliver back to NHS England and to regulators. This includes use of systems such as Bluteq, as well as bespoke datasets based on service specifications. Clinical and patient organisations also maintain a number of high quality registries.

"Quality can be difficult to measure given existing data gaps...Detailed metrics would allow for the benchmarking of national standards" – MS Trust and MS Society

\textsuperscript{30} NHS England, \textit{Specialised Services Formula}, April 2016, p. 27
UK Cystic Fibrosis Registry

The UK Cystic Fibrosis (CF) Registry is a national, centralised web-based database that collects demographic, health and treatment data on consenting people with cystic fibrosis from every CF care centre in England, Wales, Scotland and Northern Ireland. The UK CF Registry is sponsored and managed by the Cystic Fibrosis Trust.

Of more than 10,000 people living with cystic fibrosis in the UK, over 99% consent to their anonymised data being collected in the Registry, which is collected by nearly 150 specialist centres and networked clinics.

It is a key evidence base for the cost of cystic fibrosis care, maximising the impact of national specialised commissioning for CF services by providing information and insight to inform commissioning behaviour across the UK.

The Registry is commissioned by NHS England to devise proportionate year-of-care payments by NHS England, creating a Payment by Results (PbR) tariff that reflects the complexity of patients’ needs in each NHS Trust.

National Congenital Anomaly and Rare Disease Registration Service

The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) was established in early 2015 to:

“Provide essential data for patients, their families, clinicians, public health, research and service delivery to improve monitoring of the frequency, nature, cause and outcomes of congenital anomalies and rare diseases.”

The service, which covers England through nine regional offices, is operated by Public Health England (PHE) and receives support from a number of rare disease charities and patient groups. The registry receives patient information (including personal details, diagnoses and current treatments) from a variety of sources, including:

- Local providers (e.g. tissue sample and screening data)
- National audits
- National data feeds (including Genomics England and Office for National Statistics)
- Existing disease registers

This data is received in a number of formats – both digital and paper – and is sent to expert registration teams across the country to be logged. Once logged, data is able to be digitally analysed before being sent to clinical teams for “quality assurance and timely feedback”. This data can also be accessed by PHE, the Department of Health and NHS England, thereby allowing for greater monitoring of service quality and delivery.
Collating and improving this information and ensuring that it can be part of the commissioning process is a key objective. The National Information Board should consider specialised services as a distinct workstream and work with NHS England’s specialised commissioning team to consult on a data strategy for specialised care.

In the current financial climate, the Commission recognises that initiatives requiring upfront investment may not be attractive to either specialised service providers or NHS England. This therefore has the potential to limit overall provider and commissioner buy-in. Furthermore, data sharing protocols are governed by strict regulation and patient privacy is paramount. NHS England’s recent experience of the care.data launch speaks to the public sensitivities on these matters.

Nevertheless, in the interests of better patient care, improved decision-making and longer term cost savings, data and information represents an essential investment for NHS England.

Given the complexity of these issues, the Commission recognises that an iterative approach might be necessary in practice, with work to develop comprehensive data proceeding with a smaller number of pilot services before being extended across the breadth of specialised care.
APPENDIX 1 – ROYAL COLLEGE OF PSYCHIATRISTS CONTRIBUTION

Note: It is not possible in a brief appendix to cover all areas and aspects of specialised mental health commissioning. Instead, illustrative examples and some service-specific commentaries are used to develop the key principles and approaches that form the core of this contribution.

1. Current arrangements for commissioning specialist mental health care services

1.1 The Health and Social Care Act 2012 outlines four factors that indicate which specialised services should be directly commissioned by NHS England:

i. The number of individuals who require the provision of the service or facility.

ii. The cost of providing the service or facility – high-cost and low-volume services cannot be provided within each CCG area, and economies of scale make provision feasible.

iii. The number (and cost) of persons able to provide the service or facility – where clinical skills are not widely available, a critical mass of skilled staff needs to be created to deliver clinically and cost-effective intervention and treatments. Importantly, this could mean that the specialist nature of a service is determined either by the low number of individuals who require a service, or its use of rarer and more complex treatments for relatively common diagnoses of mental disorder (see service-specific commentaries, below).

iv. The financial implications for Clinical Commissioning Groups (CCGs) if they are required to arrange for the provision of the service or facility.

1.2 Running through all four factors is the fact that clinical specialists are likely to be far more effective than generalists in delivering optimised and well-managed treatments. Commissioning needs to consider the whole care pathway, and where appropriate to bring together and pool CCG and specialist commissioning budgets to manage this and fully adhere to full NICE guidelines.

1.3 To address inconsistencies in definition and implementation, specialised mental health services should be subject to national standards to ensure equivalent services and consistency across the country. This would avoid situations such as those reportedly
existing in gender identity services, where commentators indicate that all seven services in England employ different assessment processes (see also service commentary, below). Assurance about national standards should be provided through commissioners, who should be clinical staff from the specialty, with real knowledge about the clinical issues that arise. There should be national leadership or an advisory group to ensure there is a clear strategy for specialist service provision.

1.4 Existing national definition sets need reviewing in light of the above, and to ensure alignment with NICE and other guidance.

2. Principles that should guide specialist mental health care provision

2.1 Parity of esteem: When making decisions about care, commissioners and providers of both mental and physical healthcare services should show that they have considered the needs of people with mental disorders. This includes, for example, patients discharged into the community from Secure Care (forensic mental health services), for whom physical healthcare can be a significant unmet need. Parity should also mean that funding and other resources are allocated so that they are proportionate to morbidity. While this is unlikely to happen very quickly, it is something that should be aimed for. Currently, it is concerning that there is under-representation of mental health practitioners in NHS England and specialist provider commissioning, and that it is not always recognised that in providing mental health care for those requiring Secure Care (e.g. transferred mentally ill prisoners posing a risk to others) significant resource is necessarily spent on security measures (physical, procedural & relational) to maintain the safety of patients, staff and the public.

2.2 Care should be provided in the least restrictive setting, closest to home, with clear step-down care pathways.

2.3 The time patients spend in specialised care should be minimised, by working to an agreed, planned clinical outcome.

2.4 Specialist services should be provided to a population base of 4-5 million, by a single management team that is clinically led, although geography might affect the precise population size.

3. Mechanisms for enabling such an approach

3.1 The current rigid separation between commissioners and providers can act against achievement of these principles. However, there is a continuing role for both, though there should be greater flexibility in the relationship between them. We recommend that some of the money (as opposed to all, or none) should follow the patient, and that there should be cost sharing across the pathway, between the originating provider, the local CCG and NHS England.

3.2 There is concern, for example in relation to child and adolescent forensic services, that if budgetary responsibilities for nationally provided services are given to local or regional
providers, the requirements of small numbers of patients with highly specialised needs might not be met.

3.3 **Care pathways need to be integrated and collaborative.** For example, Perinatal Psychiatry services have benefited greatly from national service commissioning, which is combined with linked outreach teams and specialist community teams that are organised at the CCG level. The epidemiology of perinatal mental illness is well defined, and the population base necessary for Mother and Baby Units is too big for 'local' or 'provider' commissioning; the mental health hub and spoke model is essential for these services. There is a need for more beds nationally and for many more specialised community teams, delivered by co-ordination of commissioning, not new systems.

3.4 **Providers require expertise in clinical case management** and incentives that act towards realising these principles. This should be supported by a central assertive bed management system, properly incentivised to make the principle possible.

3.5 We need to **optimise our enabling legal frameworks**, Mental Health Act, Mental Capacity and Court of Protection, matching the pace and process of Ministry of Justice (MOJ) decision making to clinical need.

3.6 **All forms of commissioning should be outcome-focused.** Data around mental health has historically been poor in comparison to the data collected on physical health, contributing to a lack of funding for mental health. The Department of Health, Secretary of State for Health, and NHS England have strongly encouraged the RCPsych to produce a set of clinical outcome measures for mental health that will have broad support among its membership; this work is ongoing. Clarity about outcomes as recommended by the College will dovetail with the proposals for ‘A Vision of Mental Health Data in 2020’ and the Secretary of State’s Information Transparency Programme. This strategy is instrumental to the development of mental health services. It aims to bring together the data that is currently collected about mental health services and allow service users, carers, managers, clinicians and commissioners to make better decisions about the design of the care they receive or provide. For Forensic Psychiatry services, sufficient resource needs to be given to the analysis of the large amount of data that is supplied by providers to NHS England to inform the planning and delivery of services. Analysis needs to be informed by clinicians to maximise understanding and ensure valid conclusions are reached.

**Summary**

3.7 There is a need for management across the whole pathway, including good quality assertive community intervention and cost sharing, with links to length of stay bed management systems covering a wider area (e.g. 4 million population). Robust commissioning governance is required across the pathway, combined with good interagency planning to promote discharge planning.
4. The wider context

4.1 Specialist mental health services are also affected by funding for other elements of the care pathway, such as social care and primary care.

4.2 For example, some of the young people with whom our members work often have overlapping mental health, social care and youth justice needs. These may be managed principally in any one of these settings, according to which of their needs predominates, or which service has been leading on service provision. The young people need all agencies to be involved in their care, but commissioning arrangements may hinder this. Joined-up leadership is required across all agencies to ensure their needs are met and the most effective outcomes achieved.

4.3 Similarly, with regard to Secure Care, the pathway frequently starts some years before presentation to Secure Care, and can be marked by deprivation, poor education, childhood adversity etc in addition to later mental disorder. These factors need to be understood and considered by CCG commissioners at a much earlier stage and also require a public health and policy approach to primary prevention.

Service-specific commentaries

A. CO9 – Mental Health services – Specialised
1. Any services in this category have to be seen as working in collaboration with secondary and primary care and not in isolation. The wheel and spoke concept is beneficial to patients and clinical services alike, allowing local dissemination of best practice.
2. The five main categories are: treatment-refractory psychoses, treatment-refractory affective disorders, treatment-refractory anxiety disorders, adult attention deficit and hyperactivity and neuropsychiatry, including the management of medically unexplained symptoms.
3. For all of these conditions, NICE recommendations should be adhered to and access should be on the basis of disability and not of diagnostic categories. For example, severe and treatment-refractory Post Traumatic Stress Disorder (PTSD) or Obsessive Compulsive Disorder (OCD) can be as disabling as psychoses.
4. The population to be served depends on the category. A range of 1-5 million people is appropriate. This is also dependent on the balance of urban v rural population.
5. The services need to aim to have a full range of medical, psychological and supportive interventions, as evidence shows that any of these used in isolation is unlikely to be as beneficial as when used in combination with the others.
6. Where they exist, good quality local services (as measured by outcomes and patient choice) should be encouraged to take on the mantle of service development and contract negotiations.

B. Secure Care (Forensic Mental Health Services)
The College’s Faculty of Forensic Psychiatry supports the principle of national standards and service specifications for Secure Care, with care planned and informed by detailed analysis and needs assessment, and delivered on a regional basis using collaborative networks,
putting provider expertise and knowledge more at the centre of service planning and
delivery. This would include:

1. Regionally based services as part of a network of Secure Care and a comprehensive care
pathway in and out of Secure Care, including into the community and returning to prison
where appropriate associated with population-based commissioning (money following the
patients).
2. Services provided as close to home as is practicable, in keeping with the Mental Health Act
Code of Practice paragraph 1.4 and the Five Year Forward View for Mental Health
recommendation. Bringing back people who have been placed out of area should be a
priority.
3. Appropriate case management with more clinician involvement to facilitate the care
pathway.
4. Recognition of the requirement to react urgently to mental health crises in secure settings
including in prison, the community and in police stations, in the same way that these crises
are recognised in primary and secondary mental healthcare settings.
5. Clearer definitions of Low Secure / Locked Rehabilitation / Enhanced Rehabilitation care,
etc. This should ensure that only those truly requiring Secure Care because of at least a
potential risk to others (rather than for example mainly being a risk to themselves) are
provided with the care they need.
6. A review of female services, to ensure that female patients are only placed in secure
services if they require this because of posing a risk to others.
7. The provision of: a) appropriate Forensic Outreach or Forensic Community Services to
guide and follow patients along the secure care pathway, facilitate discharge at the earliest
appropriate time, and provide follow-up care in the community where appropriate, ensuring
other services are in place in a timely and efficient manner and b) step down accommodation
to facilitate egress into the community, as recommended in the Five Year Forward View for
Mental Health. This provision should recognise the risks and delays that junctures and
transitions in care provision pose and seek to minimise these.

This would ensure all patients wherever possible receive the care they need as close to their
home and families as possible. If structured and managed appropriately, it is highly likely to
be a more efficient use of resources and reduce risks of patients being stuck in the
system, particularly out of their home area. The prime contractor model may be a means
of achieving this. Notwithstanding, there is a need for some patient groups to have
commissioning at a more supra-regional or national level, such as: Secure Care for deaf
people, brain injury and some, though not all, women’s services. However regionally-based
service planning and commissioning needs also to take their needs into account, for example
stepping down closer to home, and community services such as Forensic Outreach that they
may need in the future.

All of the above must also apply to patients with learning disability and autistic
spectrum disorder who require Secure Care. This group should also be afforded the
benefits of national quality standards, service specifications and a national needs
assessment in planning service provision, something that may be at risk with the
implementation of the Transforming Care for People with Learning Disabilities report
recommendations, if not explicitly acknowledged.
Currently, many CCG Commissioners are unlikely to have the expertise or detailed understanding of Secure Care and particularly all of its sub-specialties, including adult men and women, Forensic CAMHS, Learning Disability, Autistic Spectrum Disorder, Neuropsychiatric disorders, etc.

C. **Personality disorder services**

Personality disorder (PD) services are currently organised in Tiers. In principle, Tiers 4-6 are commissioned nationally and Tiers 1-3 locally. In practice, the shortage of national PD provision leads to CCG commissioning of private Tier 4 PD and locked rehab beds. There is evidence that outcomes are improved and costs reduced by investing in local specialist PD pathways to repatriate patients in secure placements, preventing delayed discharges and diverting patients who would otherwise require placement. The cost savings are invested in:

- Psychotherapeutic provision appropriate to the risks and complexity of the patients
- Training for professionals across agencies in work with PD.

This improves care and access to therapies for all PD patients presenting to services. However, it does require investment in local psychotherapeutic pathways.

D. **Child and Adolescent Mental Health Services (CAMHS)**

For CAMHS, the need for more expensive inpatient admission could be minimised by investment that strengthens community mental health services. There is also a need for investment in Tier 3.5/alternatives to admission and Urgent and Emergency Care, and changes to the commissioning and provider relationships (NHS-E: CCGs: inpatient providers) that enable financial risk sharing to support this. This could be via commissioning of the whole pathway but this entails crossing the border between local specialist (i.e. Tier 3) services and specialist inpatient services. This may be more possible with regional commissioning. It also entail incentivising inpatient providers (esp. in the private sector) to facilitate discharge. While it is outside the remit of CCG/NHS-E commissioners, improved provision of social care placements is also vital.

E. **Deaf Mental Health services**

Specialised Deaf MH services reduce risks and lengths of hospital admission for Deaf people. They ensure accurate and timely diagnoses and treatment and can avoid hospital admissions or reduce lengths of stay. Deaf people value access to services that are deaf-aware, where their cultural and communication needs are met.

Currently the split between direct commissioning from NHS England and CCGs is unhelpful as funding has been lost for Deaf IAPT services. However, this is such a small population that it is difficult for CCGs to build expertise in commissioning. The specialised centres provide excellent care but patients have to travel. Deaf people do not have the same geographical coverage of services as hearing people; neither do they have the same access to the same the same range of services. The specialist services would like to see better access to MH services at primary care level, better access to voluntary services (Samaritans, AA) and better provision at secondary care e.g. every Community Mental Health Team (CMHT) having a
Deaf champion. The specialist centres could build on existing models using telepsychiatry and similar to support provisions in primary and secondary care.

There also needs to be better Deaf Awareness in A and E and in relation to immigrant populations, where there are high levels of deafness and mental health problems, but poor access into primary care and secondary care MH services. Secondary MH services often offer Recovery Colleges or similar. However, Deaf people have problems accessing these, both because they need interpreters but also because of a lack of deaf awareness. We would advocate that better access to local recovery resources would improve outcomes for this group.

If accountability is devolved to CCGs, the risk is that they will see too few Deaf people to commission for them; however, the current split in commissioning between CCG and specialised NHS England is holding up innovation.

**F. Gender Identity services**

There is much positive emphasis on moving trans people away from having a psychiatric disorder, while still recognising the major mental health component of their health needs. This requires better understanding among psychiatrists, physicians and GPs to help support the inclusion of trans people in mainstream health care, in a context of gender affirmation and de-pathologisation across the spectrum, so that people are better able to self-identify, be accepted and receive the care they need. This should include easy access to surgery, medical affirmation and legal affirmation.

However, there will always be a need for specialised psychiatrist-led mental health services for trans people, some of whom present with co-morbid personality/borderline personality problems, linked to issues such as increased sexual abuse among trans people experienced when young. With these and other issues in the background, it is often more difficult for these individuals to receive care through a defined pathway, and they need access to specialist care and support for their psychological turmoil. This should be complemented by training and support for people working with these individuals in community settings.

As stated above, all seven specialist centres in England have different assessment processes; there needs to be clearer understanding and agreement to develop a standard assessment. In the community, there could be development of GPs with a specialist interest in this area of health care.

All services need to recognise that there is a fluidity of gender definitions, a spectrum, rather than working with the binary concept of male/female.

April 2016
APPENDIX 2 – SPECIALISED SERVICES EXTERNAL ENGAGEMENT

In order to broaden the scope of the Commission’s deliberations, it was agreed that a call for evidence would be issued to external stakeholders. The call for evidence covered the following key areas:

- Safety, Quality and Money
  - How should specialised services be defined?
  - Is growth in expenditure on specialised services necessarily faster than the general rate of NHS growth? If so, how should this be accommodated?
  - How can quality best be embedded in specialised services? Should national standards remain in place and how should quality be assured?
  - How and at what level should clinical leadership and patient involvement be embedded for specialised service planning?

- Provision and integration
  - What role should providers play in the management of specialised care in future?
  - How should the provider landscape change? What role will New Care Models play?
  - How should payment systems adapt to support better specialised care in future?
  - What measures would best support an integrated experience of specialised care for patients?

- Accountability and engagement
  - How will accountability for patients and the public be assured in a more plural world?
  - How should devolution affect specialised services and what safeguards will be required?
  - Where should the buck stop and how will patients and the public know who to engage with?
  - How should the Commission consider innovation within the above programme, without duplicating the work of the Accelerated Access Review?

In response to this call for evidence, 33 submissions were received from a variety of patient organisations, Royal Colleges, industry bodies and companies. These are set out below:
<table>
<thead>
<tr>
<th>Patient organisations</th>
<th>Professional organisations</th>
<th>Industry</th>
<th>Royal Colleges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anthony Nolan</td>
<td>Association of the British Pharmaceutical Industry</td>
<td>AbbVie</td>
<td>Royal College of Anaesthetists</td>
</tr>
<tr>
<td>Asthma UK</td>
<td>Academy of Medical Royal Colleges</td>
<td>Actelion</td>
<td>Royal College of Obstetricians and Gynaecologists</td>
</tr>
<tr>
<td>Bliss</td>
<td>British Academy of Childhood Disability</td>
<td>Baxter</td>
<td>Royal College of Ophthalmologists</td>
</tr>
<tr>
<td>British Kidney Patient Association</td>
<td>British Association for Paediatric Nephrology</td>
<td>Novartis</td>
<td>Royal College of Paediatrics and Child Health</td>
</tr>
<tr>
<td>British Liver Trust</td>
<td>British Cardiovascular Society</td>
<td></td>
<td>Royal College of Physicians of Edinburgh</td>
</tr>
<tr>
<td>British Pain Society</td>
<td>British Society for Paediatric Endocrinology and Diabetes</td>
<td></td>
<td>Royal College of Psychiatrists</td>
</tr>
<tr>
<td>Combat Stress</td>
<td>European Medicines Group</td>
<td></td>
<td>Royal College of Radiologists</td>
</tr>
<tr>
<td>Chronic Pain Policy Coalition</td>
<td>Faculty of Pain Medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor Neurone Disease Association</td>
<td>Health Foundation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MS Society and MS Trust (Joint submission)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National AIDS Trust</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Niemann Pick UK</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teenage Cancer Trust</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 3 – THE CHAIR AND THE SECRETARIAT

Lord Warner has played a significant role in the development of the NHS over the past decade. As Minister for NHS Reform under the Blair government, Lord Warner commissioned Sir David Carter to examine the specialised commissioning system in England and how improvements could best be made. He also served as the government’s spokesperson for health from 2003 to 2006 and has since been involved in commissions covering social care funding, children’s homes and local government services.

Prior to his elevation to the peerage in 1998, Lord Warner held senior civil service positions in the Ministry of Health, Department of Social Security and the Home Office. Formerly a Labour member of the House of Lords, Lord Warner resigned the party whip in 2015 and now sits as a non-affiliated peer.

THE SECRETARIAT

Members of the Specialised Healthcare Alliance (SHCA) agreed to grant the Commission use of its secretariat. This has been without prejudice to the Commission’s policy positions, discussions and recommendations.

JMC Partners currently provides the secretariat to the Specialised Healthcare Alliance.
APPENDIX 4 – MEMBERS AND OBSERVERS OF THE SPECIALISED SERVICES COMMISSION

MEMBERS

Professor Dame Sue Bailey
Chair
Academy of Medical Royal Colleges

Professor Tim Briggs
National Director of Clinical Quality and Efficiency
Department of Health

Chris Hopson
Chief Executive
NHS Providers

Professor Maureen Baker
Chair
Royal College of General Practitioners
Report of the Specialised Services Commission

Robin Bhattacherjee
General Manager
Actelion (representing the ABPI)

Gina Lawrence
Specialised commissioning lead
Greater Manchester health and social care/NHS Trafford CCG

Professor Jane Maher
Chief Medical Officer
Macmillan Cancer Support

Ed Owen
Chief Executive
Cystic Fibrosis Trust

Richard Rogerson
Trustee
Niemann Pick UK

Julie Wood
Chief Executive
NHS Clinical Commissioners
OBSERVERS

Deirdre Evans
Director
Scottish National Services Division

Fiona Marley
Head of Highly Specialised
NHS England

Daniel Phillips
Director of Specialised Services
NHS Wales
APPENDIX 5 – SPECIALISED SERVICES COMMISSION TERMS OF REFERENCE

Purpose of the Commission
The Specialised Services Commission is an independent working group convened by Lord Warner on the tenth anniversary of the publication of the Carter Review into specialised services. The Commission is intended to bring together perspectives from across the health service to develop recommendations for the future shape of specialised service planning and provision across the UK.

Scope of the Commission
The Commission will agree a scope for its activities at its first meeting in December 2015. This will be based on the need to take into account core patient-centred principles:

- Specialised care should be equitable, leaving no-one behind
- Patients should be assured of appropriate specialist involvement in their care
- Systems and processes should be focused on maximising patient outcomes
- Specialised care should be delivered as close to patients’ homes as possible
- Patients should be involved in decisions about their care, including future service development
- Patients and the public should be able to hold the NHS to account for the quality of specialised care

Membership of the Commission
The Commission is comprised of senior leaders from across the commissioning and provider sectors, as well as a range of patient organisations and other key representatives from across the UK. NHS England is an observer to the Commission and will contribute to its discussions without prejudice to the group’s recommendations.

Term and Chair
The Commission will meet four times between December 2015 and April 2016, at which point its recommendations will be published and the group will disband. Lord Warner is the Chair of the Commission.

Secretariat
The Commission will be serviced by the Specialised Healthcare Alliance’s secretariat. This is without prejudice to the Commission’s policy positions, discussions and recommendations. JMC Partners currently provides the secretariat to the Specialised Healthcare Alliance.

Funding
Members of the Commission will give their time unpaid as a function of their independence. The Specialised Healthcare Alliance has agreed to provide the Commission use of its secretariat. Further information about the Specialised Healthcare Alliance and its funding is available on its website, www.shca.info/.