National Audit Office

Report
by the Comptroller
and Auditor General

Department of Health and NHS England

The commissioning of specialised services in the NHS

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National Audit Office

Department of Health and NHS England

The commissioning of specialised services in the NHS

Report by the Comptroller and Auditor General

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Sir Amyas Morse KCB
Comptroller and Auditor General
National Audit Office

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This report assesses whether NHS England is delivering value for money from its commissioning of specialised services.

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Contents

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Key facts

146
specialised services in England, in 2015-16

£14.6bn
budget for specialised commissioning in 2015-16

7%
growth rate in the budget for specialised commissioning for 2016-17

Around 300	health organisations provide at least one specialised service
489	full-time equivalent staff working for NHS England on the commissioning of specialised services in 2015-16, compared with 287 full-time equivalent staff in 2013-14
63%	of spend on specialised services is accounted for by ten service areas (groups of specialised services)
£2.7 billion	total cost of specialised cancer services in 2014-15
£2.6 billion	total estimated cost of high-cost drugs in 2015-16

Summary

1 Specialised services are generally provided in relatively few hospitals and accessed by small numbers of patients. They are usually for patients who have rare conditions or who need a specialised team working together at a centre. There are currently 146 specialised services, covering a diverse range of disparate and complex services. These range from services for long-term conditions, such as renal (kidney) and specific mental health problems, to services for uncommon conditions such as rare cancers. Appendix One provides a full list of these services.

2 Some specialised services, such as those for cystic fibrosis, cover the majority of care for patients with these conditions. However, most specialised services only form a part of a patient's care and treatment pathway. Some highly specialised services, including those for very rare diseases, are only provided at a very small number of centres across the country. Others, such as chemotherapy services, are provided by most acute hospitals.

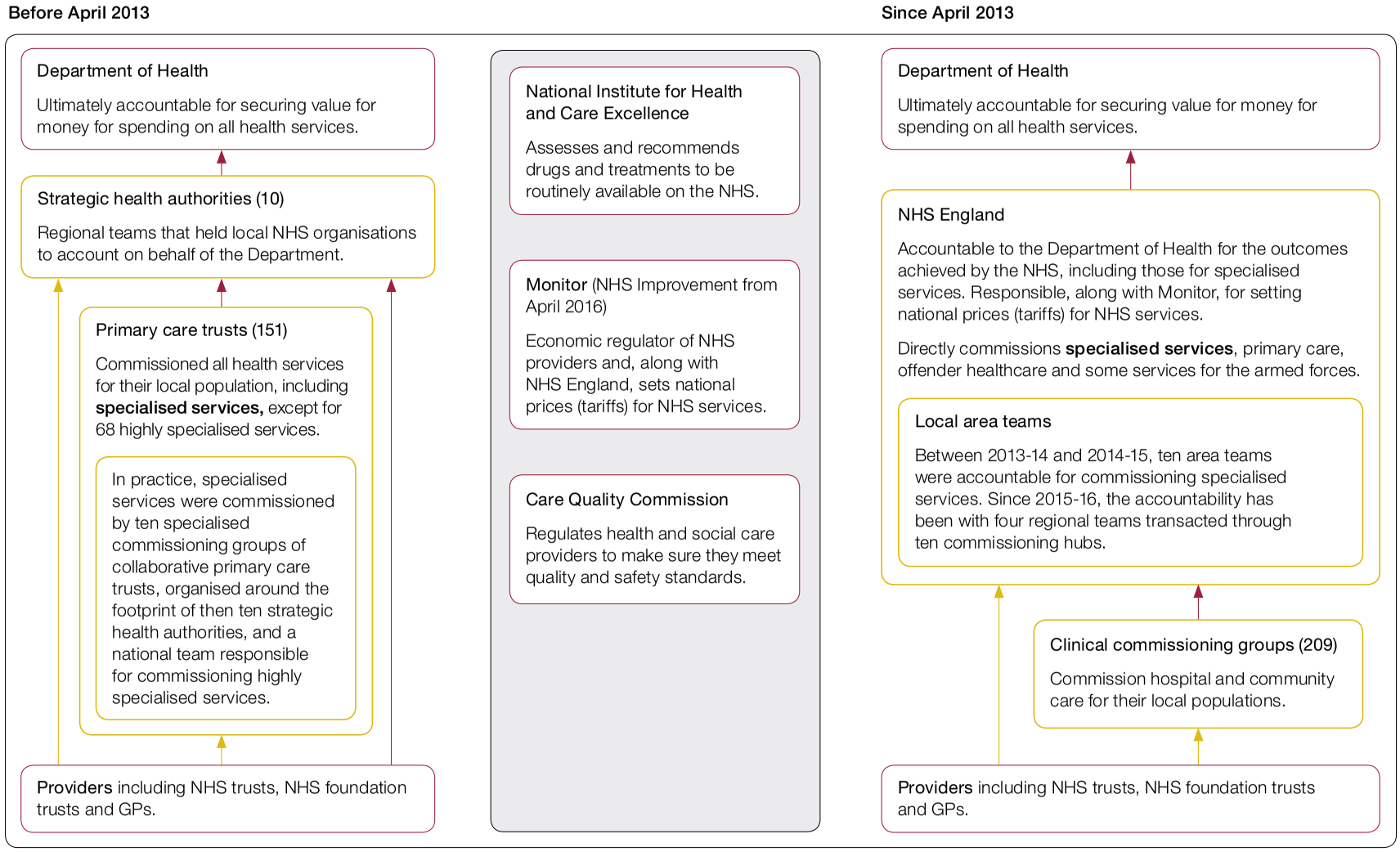
3 In April 2013, NHS England took on responsibility for commissioning specialised services, including setting the budget for these services (**Figure 1** overleaf). Before this, ten strategic health authorities were responsible for commissioning highly specialised services and 151 local primary care trusts were responsible for commissioning all other specialised services. The Secretary of State for Health is responsible for deciding which services should be commissioned as specialised services by NHS England. Through its commissioning of specialised services, NHS England aims to: improve outcomes for patients; ensure patients have equal access to services regardless of location; and improve productivity and efficiency.

4 Health is an area of public spending that the government has protected in recent years compared with most other areas of government spending. However, finances have become increasingly tight, with health funding rising at a historically low rate of 1.8% in real terms between 2010-11 and 2014-15. The NHS *Five Year Forward View*, published in October 2014, estimated that there would be a £30 billion gap between resources and patient needs by 2020-21 and set out proposed changes to the provision of healthcare services to meet this gap.

5 Specialised services can be expensive to provide. In 2015-16, the budget for these services was £14.6 billion. This is about 14% of the total NHS budget. Commissioning these services effectively will be crucial for enabling the NHS to adapt to increasing patient demand, new treatments and technologies and funding constraints. If NHS England is unable to keep its spending on specialised services within budget, this will affect its ability to resource other services, such as primary care, non-specialised hospital and community services, and wider health transformation set out in the *Five Year Forward View*.

Figure 1

The commissioning of specialised health services before and after April 2013



Source: National Audit Office

Our report

6 This report assesses whether NHS England is delivering value for money from its commissioning of specialised services (excluding the Cancer Drugs Fund, which we covered in a separate report)[1] and examines whether:

- NHS England has an overarching vision for the commissioning of specialised services and an effective plan to achieve this vision (Part Two);
- NHS England has the capacity and capability to commission specialised services effectively, including managing the budget and improving productivity and efficiency (Part Two); and
- NHS England is able to gain assurance that it is achieving its objectives to ensure equity of access to specialised services and improve patient outcomes (Part Three).

Part One gives an overview of specialised services in England and the challenges that NHS England faces in commissioning these services. We set out our audit approach in Appendix Two and evidence base in Appendix Three.

Key findings

Managing the budget for specialised services

7 Spending on specialised services is expected to increase at a much greater rate than other parts of the NHS. In December 2015, NHS England announced that the budget for specialised services would increase by 7.0% for 2016-17, compared with an increase in the budget for clinical commissioning groups (which commission the non-specialised acute and community NHS services for their populations) of 3.4% and an increase in the budget for primary care services of 4.2%. NHS England's board noted that keeping within the future budget for specialised services would be exceedingly challenging, as it had limited its cost estimate on potential new drugs and devices to the lowest end of its projected range. Between 2013-14 and 2015-16, the budget for specialised services increased from £13.0 billion to £14.6 billion, an increase of 6.3% a year on average. Over this period the budget for the NHS as a whole increased by 3.5% a year on average (paragraphs 1.8 and 1.9).

8 NHS England has found it challenging to live within its budget. NHS England found it challenging to keep within its 2013-14 budget for specialised commissioning because the original budget was based on poor-quality data. Although it increased its budget during the year, it still overspent the revised budget by £377 million (2.9% of the budget), of which £31 million was for the Cancer Drugs Fund. Improvement in budget management reduced the overspend to £214 million (1.5% of the budget) in 2014-15, £136 million of which was accounted for by the Cancer Drugs Fund. NHS England reported an overspend of £142 million for the first ten months of 2015-16, of which £110 million was for the Cancer Drugs Fund (paragraphs 2.10 and 2.11).

1 Comptroller and Auditor General, *Investigation into the Cancer Drugs Fund*, Session 2015-16, HC 442, National Audit Office, September 2015.

9 A number of factors are creating financial pressures for specialised services, in particular the increasing volume of effective but expensive new drugs. Factors contributing to the rising budget include: increasing demand, at a faster rate than demand for non-specialised services; increasing use of high-cost drugs and devices to treat previously untreatable conditions or new, more effective products to replace older ones, often at a higher price; and new services being added to the specialised services portfolio. For example, in 2015-16 an additional £191 million (1.3% of the budget for specialised services) was required to pay for new drugs to treat Hepatitis C. It is difficult for NHS England to secure these drugs at lower prices once the National Institute for Health and Care Excellence (NICE) approves them for use. NICE assesses the clinical and cost-effectiveness of new drugs, but does not consider affordability. However, where a drug is not assessed or not recommended by NICE, NHS England has discretion over whether to fund the drug (paragraphs 1.11 and 2.12).

10 NHS England and Monitor have sought to control the cost of services by reducing the prices paid (tariff) for NHS services, but this may have impacted on providers' financial sustainability. In both 2013-14 and 2014-15, NHS England and Monitor required NHS trusts to deliver 4% efficiency savings, set within the price paid to NHS trusts for all NHS services, including specialised services. In 2015-16, 88% of NHS trusts opted for a tariff arrangement that included a 3.5% efficiency saving, and introduced a marginal rate where they were paid 70% of the tariff for specialised services above a level of activity agreed with their commissioners. The remaining 12% of trusts stayed on the previous tariff arrangements. NHS trusts, as a whole, have found these tariff arrangements challenging over the past few years. Trusts that have a high proportion of their income from specialised services are still in a better financial position than those trusts with less income from specialised services. However, despite this, our analysis indicates that their financial position has deteriorated significantly over the past two years (paragraphs 2.18 to 2.21).

Capacity and capability to commission specialised services

11 National-level contracting has strengthened NHS England's position to influence providers and reduce prices but it is not clear whether its commissioning hubs have the skills to manage these contracts effectively. NHS England introduced national service specifications that all trusts are expected to meet. However, in 2015-16, 38% of trusts were not compliant with one or more service specifications. NHS England limits its contracts with providers to 12 months (with a few exceptions). Only 6% of acute trusts responding to our survey reported that their current contract with NHS England enables them to plan services for the long term. NHS England told us that, from 2016-17, it plans to increase the duration of contracts with selected providers to between two and five years. In addition, stakeholders raised concerns that NHS England's commissioning hubs do not always have the commercial skills necessary to manage contracts with providers effectively (paragraphs 2.15 to 2.17 and 3.8).

12 NHS England underestimated the scale of the challenge of commissioning 146 specialised services. In its first year of operation, NHS England focused more on getting clinical commissioning groups up and running, and less time was focused on its own commissioning functions. In 2014-15, NHS England identified a need to increase its resources for commissioning specialised services. It increased the budget from £20 million with 307 full-time equivalent staff in 2014-15, to £38 million with 489 full-time equivalent staff in 2015-16 (paragraphs 2.2 and 2.3).

13 It is not clear how the commissioning of specialised services sits within the NHS *Five Year Forward View*. NHS England has yet to develop an overarching vision, or strategy, for specialised services. Although NHS England publishes its commissioning intentions for specialised services each year, NHS acute trusts and clinical commissioning groups told us that NHS England had not communicated a clear strategy for specialised services and this had affected their ability to plan services effectively. NHS England told us that, given the level of resources it has had, it has prioritised managing transactions with providers with only limited focus on strategic issues to develop specialised services and improve patient outcomes (paragraphs 2.4 and 2.5).

14 NHS England's original governance arrangements for the commissioning of specialised services were ineffective and stakeholders have raised concerns about the transparency of decision-making. The governance structure for specialised services is complex and has changed a couple of times since April 2013. These complex and changing arrangements may have hindered its ability to develop its specialised commissioning function. Despite repeated requests from various stakeholders, NHS England has not made public most of its meeting notes or board papers relating to how decisions are made as to which new treatments are funded by specialised services. In late 2015, it started publishing meeting minutes of the Patient and Public Voice Assurance Group for specialised services (paragraphs 2.6, 2.7, 3.6 and 3.14).

15 NHS England does not have the information it needs to drive service improvements in specialised services. For some services (accounting for about one-third of total expenditure), payments are based on the level of activity and unit price (tariff) set at national level. In these cases, NHS England knows how much it spends on each service area and what services patients receive. But for the remaining services, including high-cost drugs and devices, and services paid for according to locally agreed prices, there are no consistent national data available because local commissioning teams collect them differently. NHS England told us that it had introduced standard reporting formats for these data in 2015-16 and that this information would be collected consistently from 2016-17. This means that NHS England is currently unable to assess and gain assurance about: how efficiently the services it commissions have been delivered; whether the level of access to specialised services has changed since 2013-14; and whether inequalities in access to services have reduced (paragraphs 2.13, 2.14 and 3.3).

16 Data, where available, indicate that there are variations in access to services, quality of services and prices paid for services. For example, in 2014-15, the number of cancer patients aged between 25 and 74 receiving chemotherapy per 100 new cancer cases varied from 42 to 77 across clinical commissioning groups (excluding the lowest and highest 5%); in February 2016, the level of compliance with national service specifications varied from 74% in the North West to 96% in East Midlands; and in 2014-15, the price paid for a kidney transplant with a live donor varied from £13,000 to £42,000 across the eight centres providing this service (paragraphs 2.14, 3.4 and 3.8).

Patient outcomes and patient experience

17 NHS England does not have the information it needs to assess whether patient outcomes are improving or whether inequalities in patient outcomes are reducing. NHS England is developing 'quality dashboards' for some specialised services. These dashboards collect a range of information on clinical processes, intermediate clinical outcomes and compliance with national service specifications or standards for individual trusts. By April 2016, it had developed dashboards for 41 service areas with six more in development. However, the data in the dashboards were often incomplete (paragraphs 3.11 and 3.12).

18 Some patients, particularly those with long-term conditions, have found their care becoming disjointed. The separation between the commissioning of specialised services and other NHS services can lead to gaps in provision and poor data sharing. NHS England has recognised this as an issue and plans to address it by developing a more collaborative approach to commissioning specialised services with clinical commissioning groups. The NHS *Five Year Forward View* set out NHS England's intention to progressively give clinical commissioning groups more influence over the total NHS budget for their local populations, including specialised services. Most clinical commissioning groups (more than 70%), that responded to our survey, support a more joined-up approach to commissioning services, but they believe more clarity about costs and better engagement with NHS England are needed (paragraphs 2.8 and 3.16).

Conclusion on value for money

19 The growth in spending on specialised services presents an ongoing risk to NHS financial stability. In the three years since NHS England became responsible for commissioning specialised services, spending on these services has increased faster than other parts of the NHS and it has not remained within the budget that it set for itself. NHS England still does not have consistent information from all providers on costs, access to services and outcomes or how efficiently services are being delivered. Without this, it cannot manage the ongoing pressure on its budget for specialised services, make effective strategic decisions or gain assurance that its objectives for these services are being met.

20 Until NHS England significantly improves its strategic and operational arrangements for the commissioning of specialised services we cannot conclude that the current commissioning arrangements are providing value for money. In order to control the future costs of specialised services and put these services on a sustainable footing, NHS England will need to get better control of rising costs, in particular, drugs costs; improve its management information; and manage demand better through service reform.

Recommendations

a **NHS England should develop an overarching strategy or vision for commissioning specialised services and communicate this clearly to stakeholders.** This should include how the vision sits within the NHS *Five Year Forward View*, and how it intends to engage with other commissioners, service providers, patients and the public in the development of these services.

b **NHS England should finalise its governance arrangements for specialised commissioning.** It should look to streamline the governance arrangements and make its decision-making processes more transparent, for example by publishing meeting minutes and board papers.

c **NHS England should move quickly to ensure it has the right information to make strategic decisions about commissioning specialised services.** This includes information systems to allow it to link spend, by service provided, to service quality, patient outcomes and patient experience. NHS England should also set out clearly how it is going to ensure that information standards are consistently enforced by its local teams. It should report, on a regular basis, to its board on the quality and availability of this information.

d **The Department of Health (the Department) and NHS England, in collaboration with NICE, should ensure that they consider overall affordability when making decisions that have an impact on specialised services.** For example:

- the Department, NHS England and NICE should work together to establish how the addition of new drugs and devices can be kept affordable within available commissioning budgets;
- the Department should ensure that NHS England has the flexibility to negotiate the best prices for the high-cost drugs it commissions nationally. For example, by working with providers to guarantee the volumes of drugs to be purchased, the NHS could potentially secure better value; and
- NHS England should ensure its commercial and financial arms are working effectively with its clinical advisory groups when setting service specifications and service standards to ensure affordability.

e **NHS England should ensure that it has the right skills in the right places to commission specialised services effectively.** Having increased its resources to commission specialised services, NHS England should assess whether it now has the commercial skills necessary to manage contracts with providers effectively. It should also assess whether its commissioning teams have the leadership required to drive service changes.

f **NHS England should work with NHS Improvement to design tariffs which help providers to adopt the most efficient service models.** The various funding arrangements currently in place for specialised services are an obstacle to transparent reporting of performance and lead to variations in prices. NHS England and NHS Improvement should clarify their long-term funding arrangements for specialised services and their intentions regarding the use of national tariffs and local tariffs. NHS England should ensure that it has the data required to enable it to understand how the variations in local tariffs are related to local practices and use this information to design tariffs to support services to adopt the most efficient service models.

Part One

Specialised services in the NHS

1.1 This part of the report provides an overview of specialised services in England, how they are commissioned, how much they cost and the factors that are contributing to the rising costs of these services.

What are specialised services and who provides them?

1.2 Specialised services are generally provided in relatively few hospitals and accessed by small numbers of patients. These services treat rare conditions or those that need a specialised team working together at a medical centre. There are currently 146 specialised services, covering a diverse range of disparate, often complex and costly services. These range from services for long-term conditions, such as renal (kidney) services, specific mental health problems and neonatal services, to services for uncommon conditions such as rare cancers and genetic disorders. Appendix One provides a full list of these services.

1.3 Some highly specialised services, including those for very rare diseases, are only provided by a small number of centres across the country. Others, such as renal dialysis (**Figure 2** on pages 14 and 15) and chemotherapy, are provided at a large number of centres. Some specialised services, such as those for cystic fibrosis and haemophilia, provide the majority of a patient's care for these conditions once diagnosed. However, most specialised services only form a part of the patient's care and treatment pathway. Due to the rarity and complexity of some conditions, it is often difficult for patients and their carers to access, and for service providers to offer, the right care and support when needed.

Figure 2
Examples of specialised services

Specialised services cover a diverse range of disparate, often complex and costly, services

Service	About the condition
Alkaptonuria service for adults	Alkaptonuria is a rare inherited disorder that causes considerable morbidity in the peak of adulthood due to severe premature destruction of the joints and spine. Disability, often severe, is the norm for those over 30 years old. About 1 in 250,000 to 1 in 500,000 people has Alkaptonuria.
Liver transplantation services	Liver transplantation is considered a highly specialised service as there are only about 600 liver transplants each year in England.
Cystic fibrosis services	Cystic fibrosis is one of the UK's most common life-threatening inherited diseases, with about 8,000 people in England living with the condition. It affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus.
Adult specialist renal services	In England, there are currently about 43,000 people receiving treatment for kidney failure, with about 5,500 people starting treatment each year. Not treating patients or withdrawing their treatment leads to death for most patients within three weeks. Of those affected: about 50% are treated with a kidney transplant; about 40% are treated with haemodialysis;[1] and about 10% are treated with peritoneal dialysis.[2]
Adult specialist services for patients infected with human immunodeficiency virus (HIV)	HIV is a virus that causes acquired immunodeficiency syndrome (AIDS), a condition in which progressive failure of the immune system allows life-threatening opportunistic infections and cancers to thrive. About 78,300 people were seen for HIV care in England in 2014.

Notes

1 Haemodialysis involves circulation of blood through a machine that removes toxins and fluid and returns the cleaned blood back into the body. This requires an initial surgical operation to join an artery and vein, or insertion of a tube into a large vein, usually in the neck, to create 'vascular access'. Most people receive three treatment sessions a week, each lasting about four hours, which can be done at home after training or in a dialysis unit under the supervision of healthcare professionals.

2 Peritoneal dialysis, which is carried out at home, involves using the peritoneum (a thin membrane that lines the inside of the abdomen) as a filter. This requires the initial insertion of a small flexible tube, known as a catheter, into the peritoneal cavity (the space that contains the bowels and other abdominal organs). A special dialysis fluid is run into this cavity and waste products are filtered into this fluid before being drained out. This exchange of 'used' with 'fresh' dialysis fluid lasts about 35 minutes and is either repeated about four times each day or performed overnight. Most patients are trained to carry out these treatments themselves but some patients have this treatment with the supervision of healthcare professionals.

Source: National Audit Office literature review

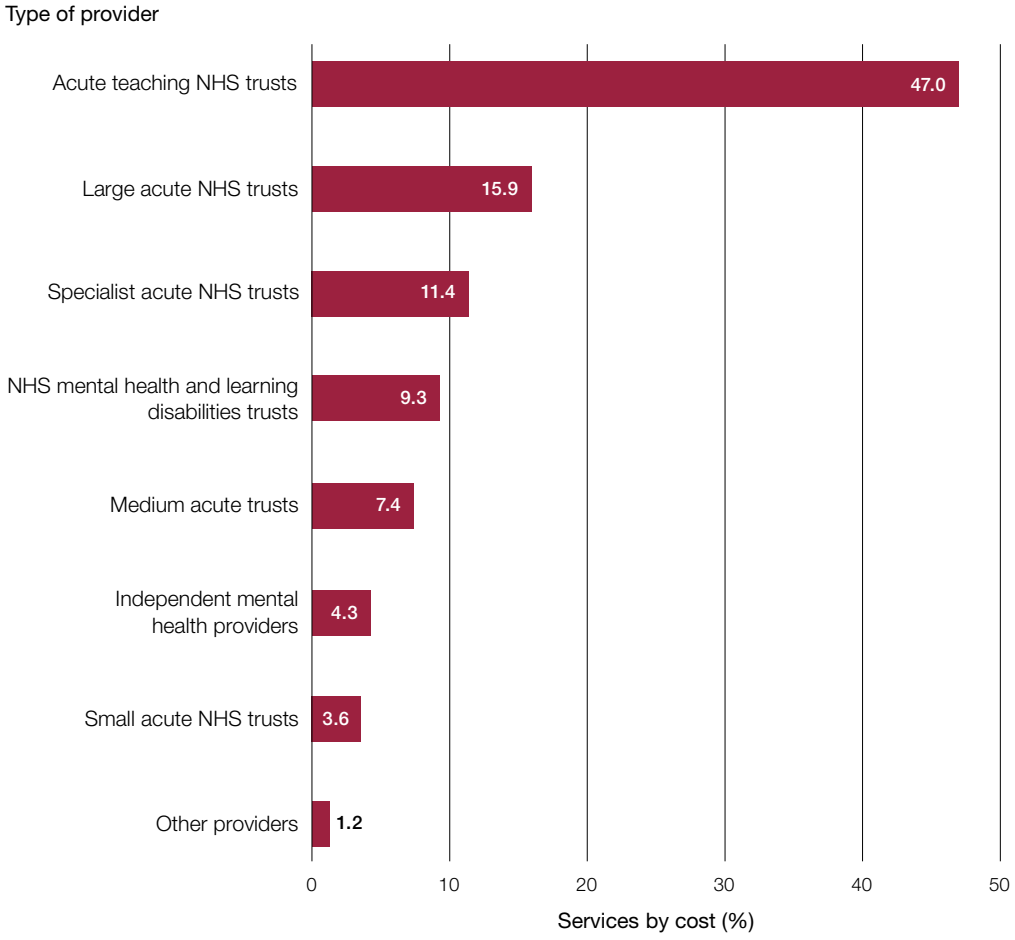
How the service is organised and what NHS England commissions	What clinical commissioning groups (CCGs) and local authorities commission
NHS England commissions this service from one national centre, which provides an inpatient-based assessment service for patients with Alkaptonuria. Patients are reviewed annually to: assess and detect disease complications; prescribe and monitor drugs to arrest the progression of the disease; and formulate shared care management plans with local providers.	CCGs commission the local care recommended in the management plan developed by the national centre.
NHS England commissions these services from seven highly specialist transplant centres, including services delivered on an outreach basis as part of a provider network. It also commissions immunosuppressive drugs, used to prevent the rejection of transplanted organs.	CCGs do not commission any elements of this service.
There are 26 NHS trusts with adult or paediatric cystic fibrosis centres, or both. Some paediatric care can be delivered close to home by local teams under the supervision of the paediatric centre. NHS England commissions all cystic fibrosis services provided by these centres, including services delivered on an outreach basis as part of a provider network. It also commissions a number of drugs used to manage cystic fibrosis.	CCGs do not commission any elements of this service. CCGs may prescribe some non-specialist drugs initiated by the cystic fibrosis centre.
There are 19 adult renal transplant centres and 52 adult specialist renal centres, all of which operate satellite haemodialysis units to reduce the distance patients have to travel to receive treatment. NHS England commissions adult specialist renal services from these centres, including services delivered on an outreach basis as part of a provider network. Services commissioned are: all chronic dialysis services; intermittent haemodialysis and plasma exchange for patients with acute kidney injury of such severity that without treatment they would die; outpatient assessment and preparation for renal replacement at these centres; all transplantation activity and transplant-related care provided by these centres. It also commissions all drugs and devices used during dialysis treatment; immunosuppressive drugs prescribed following renal transplantation; and some other drugs.	CCGs commission local inpatient and outpatient non-specialist renal services, including services for acute kidney injury for patients not requiring dialysis or plasma exchange (most non-specialist renal patients have chronic kidney disease, that is not so severe as to warrant treatment with either dialysis or transplantation); transport for haemodialysis patients; and continuous haemodialysis/filtrations treatments when used as a component of intensive and high-dependency care, when the primary reasons for admission is not acute kidney injury.
There are currently more than 50 providers of HIV services. Affected individuals are concentrated in cities, particularly London (46% of patients). NHS England commissions HIV services from adult specialist HIV centres, including the inpatient care provided by the centres and outpatient care, which may be delivered on an outreach basis as part of a provider network. NHS England also commissions a number of drugs used in the treatment of HIV.	CCGs commission promotion of opportunistic testing and treatment of sexually transmitted infections. Local authorities commission testing of sexually transmitted infections, including HIV. They also commission sexual health advice, prevention and promotion.

1.4 Around 300 health organisations provide at least one specialised service, though the majority of services (74.3%), by cost, are provided by acute teaching, large acute and specialist acute NHS trusts (**Figure 3**). In 2014-15, 28 acute teaching trusts and 20 specialist acute trusts accounted for 58% of specialised services activity by cost.

Figure 3

Specialised service providers by cost of service, 2014-15

The majority of services are provided by acute teaching, specialist acute and large acute NHS trusts



Notes

1 'Other providers' includes: independent acute providers; NHS ambulance trusts, care trusts, community trusts and multi-service acute trusts. The size of a trust is based on their number of beds. Specialist acute trusts are regional or national centres providing specialised care, and teaching trusts are attached to universities and help to train health professionals.

2 Total may not sum due to rounding.

Source: National Audit Office analysis of NHS England data

How are these services commissioned?

1.5 Since April 2013, NHS England has been responsible for commissioning specialised services under the National Health Service Act 2006, as amended by the Health and Social Care Act 2012. **Figure 4** on pages 18 and 19 shows the major developments in the commissioning of specialised services since June 2012. The Secretary of State for Health is responsible for deciding, on the recommendation of the Prescribed Specialised Services Advisory Group, which services should be included as specialised services and commissioned directly by NHS England nationally, rather than by clinical commissioning groups, that commission most health services for their local population. The Prescribed Specialised Services Advisory Group is appointed by the Department of Health, and made up of representatives from the royal colleges, NHS England, clinical commissioning groups and lay members representing the interests of patients and the general public. The Act set out four factors that should be considered when determining whether NHS England commissions a service as a prescribed specialised service:

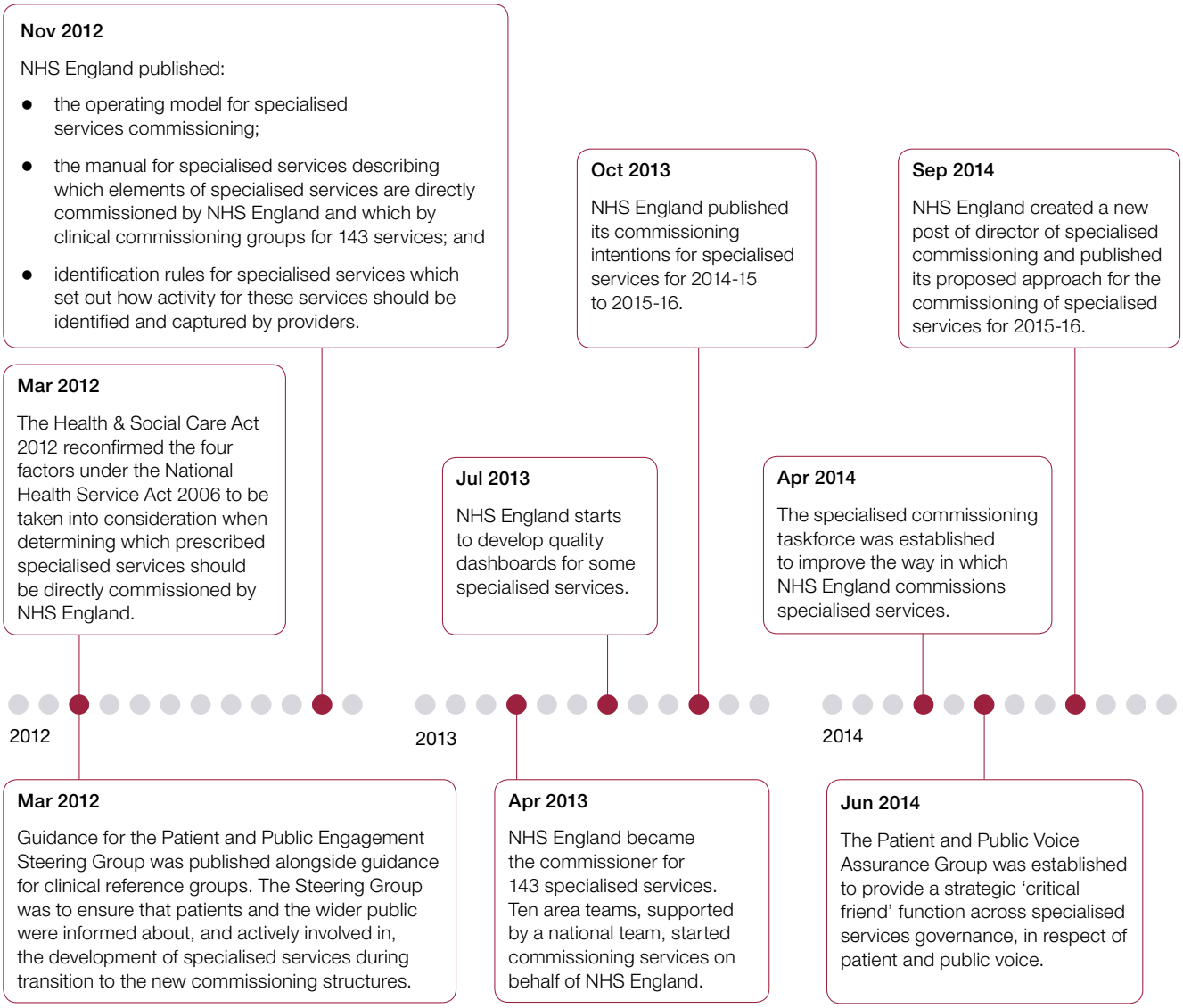
- the number of individuals who require the provision of the service or facility;
- the cost of providing the service or facility;
- the number of people able to provide the service or facility; and
- the financial implications for clinical commissioning groups if they were required to arrange for provision of the service or facility themselves.

1.6 **Figure 5** on page 20 shows the main differences in the commissioning of specialised services before and after April 2013. In April 2013, NHS England introduced a national decision-making process for specialised services that aimed to: improve outcomes for patients; ensure patients have equal access to services regardless of location; and improve productivity and efficiency.

1.7 Before April 2013, 151 primary care trusts were responsible for commissioning all NHS services for their local population, including specialised services, except for 68 highly specialised services. In practice, specialised services were commissioned by ten specialised commissioning groups of collaborative primary care trusts, organised around the footprint of then ten strategic health authorities, and a national team responsible for commissioning highly specialised services. These regional groups operated in different ways, in areas such as setting budgets, negotiating contracts and managing performance. This resulted in differential access to services with different service standards and specifications for services across the groups. There was also variation in the prices paid across the country for some services.

Figure 4

Major developments in the commissioning of specialised services since 2012



Source: National Audit Office literature review

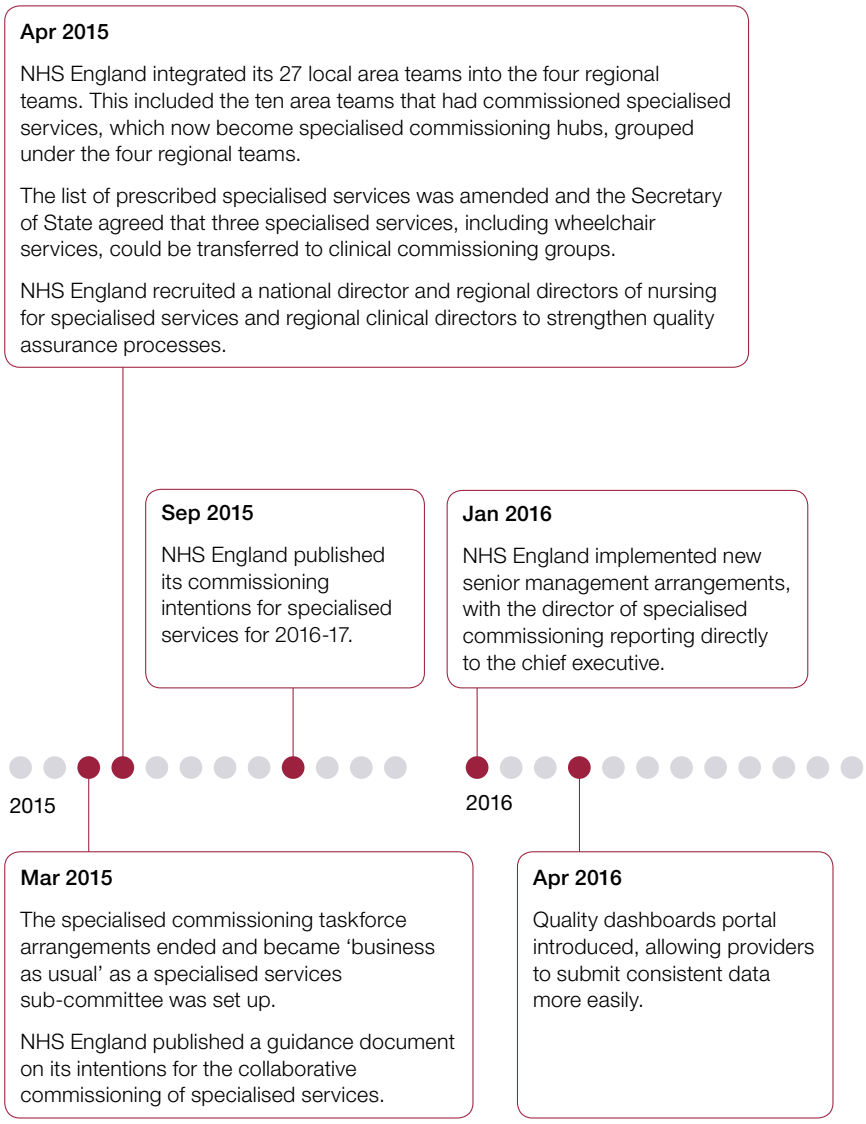

Apr 2015
NHS England integrated its 27 local area teams into the four regional teams. This included the ten area teams that had commissioned specialised services, which now become specialised commissioning hubs, grouped under the four regional teams.
The list of prescribed specialised services was amended and the Secretary of State agreed that three specialised services, including wheelchair services, could be transferred to clinical commissioning groups.
NHS England recruited a national director and regional directors of nursing for specialised services and regional clinical directors to strengthen quality assurance processes.
Sep 2015
NHS England published its commissioning intentions for specialised services for 2016-17.
Jan 2016
NHS England implemented new senior management arrangements, with the director of specialised commissioning reporting directly to the chief executive.
2015
2016
Mar 2015
The specialised commissioning taskforce arrangements ended and became 'business as usual' as a specialised services sub-committee was set up.
NHS England published a guidance document on its intentions for the collaborative commissioning of specialised services.
Apr 2016
Quality dashboards portal introduced, allowing providers to submit consistent data more easily.

Figure 5

Main differences in the commissioning of specialised services before and after 2013

	Before April 2013	After April 2013
Commissioner	Ten separate, regionally based groups and a national team responsible for commissioning highly specialised services. The regional groups consisted of constituent primary care trusts that collaborated to host this function.	NHS England through ten area teams (now commissioning hubs).
Portfolio and budget	Sixty-eight highly specialised services plus a number of other specialised services with an estimated cost of £6 billion in 2012-13. There was no consistent definitions for specialised services, leading to significant variations in numbers and types of specialised services commissioned regionally.	Budget of £13 billion in 2013-14 for 143 specialised services.
Funding	National budget for 68 highly specialised services plus subscriptions by local primary care trusts for other specialised services.	Specific NHS England budget.
Decision-making process	Regional groups operated in different ways according to the particular agreements and arrangements with their constituent primary care trusts. This resulted in commissioning variation and differential access to services with different service standards and specifications for services across the groups.	A national decision-making process with national service specifications and standards.
Contract arrangements	Multiple contracts for a single provider. Contract arrangements differed across primary care trusts.	A single contract for all specialised services provided by a single provider.
Performance monitoring	No national benchmarking data.	National benchmarking data collected for compliance with service specifications. National quality assurance framework introduced in 2014-15.

Source: National Audit Office literature review

How much do these services cost?

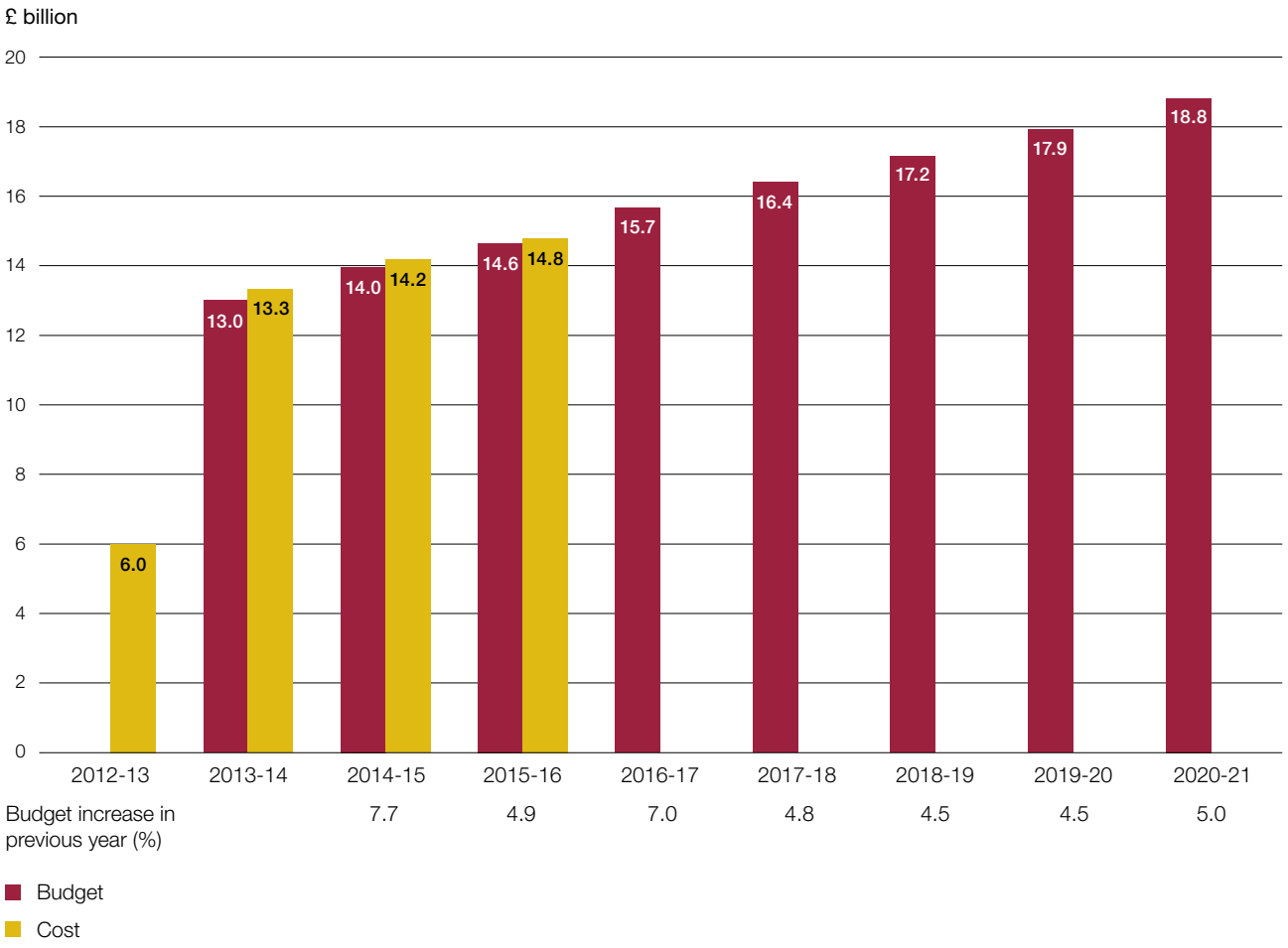
1.8 Between 2013-14 and 2015-16, NHS England increased its budget for specialised services by 6.3% a year on average (**Figure 6**), almost twice the rate of increase of its total budget (3.5% a year) over this period. In 2015-16, the budget for specialised services was £14.6 billion – 14.4% of the total NHS England budget. In 2014, NHS England estimated that, if no action was taken to control the costs of specialised services, they would rise by 7.2% a year on average over the next five years.

1.9 In December 2015, NHS England announced that for 2016-17, it would increase the budget: for specialised services by 7.0%; for clinical commissioning groups by 3.4%; and for primary care services by 4.2%. The budget for specialised services will then rise, by 4% to 5% a year, to £18.8 billion in 2020-21, or 15.8% of the total NHS budget. NHS England's board noted that, due to the licensing of an increasing volume of effective but expensive new drugs and devices, over which NHS England had no discretion, there was a risk that the budget would not be sufficient for other potential additions to specialised services in 2016-17 and beyond.[2]

2 NHS England board paper, *Allocation of resources to NHS England and the commissioning sector for 2016-17 to 2020-21*, December 2015.

Figure 6
Budget and cost of specialised services

NHS England plans to increase its budget for specialised services to £18.8 billion by 2020-21



Notes

1 The figure for 2012-13 only represents a subset of specialised services included from 2013-14.

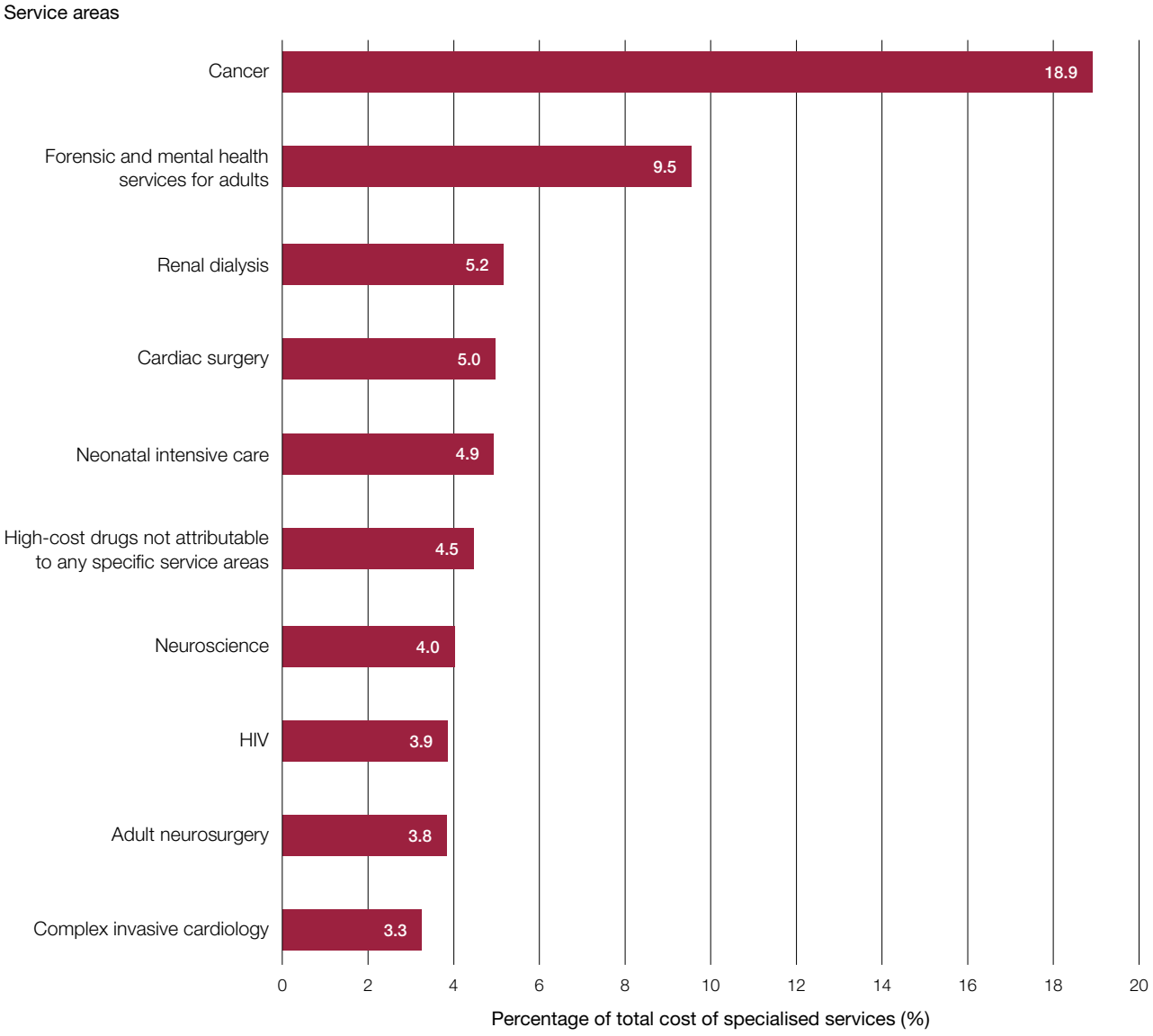
2 The cost for 2015-16 is a forecast taken from NHS England's board paper in March 2016.

Source: National Audit Office analysis of NHS England data

1.10 Although NHS England commissions a wide range of discrete specialised services, a few service areas (groups of specialised services) account for most of its spending. In 2014-15, ten service areas accounted for 63% of the costs of specialised services (**Figure 7**).

Figure 7
Specialised services with the highest costs, 2014-15

Ten service areas account for 63% of all spending on specialised services



Note

1 A service area may contain more than one specialised service. For example, cancer includes services for patients with rare cancers and radiotherapy services.

Source: National Audit Office analysis of NHS England data

What is driving the rising costs of specialised services?

1.11 **Figure 8** overleaf sets out the factors that are contributing to the rising costs of specialised services. The main factors are:

- **Rising demand.** An expanding and ageing population is increasing demand for all health services. Contributing factors may include: the rise in conditions related to age and lifestyle, such as cancer; innovation leading to more people being diagnosed and treated; and better awareness of the services available by patients and clinicians. Demand for specialised services is growing faster than demand for other health services, and is sensitive to the increasing availability of new medical interventions. Sometimes, one or two new drugs can lead to a large increase in costs. For example, in 2015-16, £191 million (1.3% of the budget for specialised services) was required to pay for new drugs to treat Hepatitis C that became available in 2014-15.[3]

- **Higher costs.** Innovation in drugs and devices can lead to expensive new treatments for previously untreatable conditions or newer, more effective products replacing older ones, but often at a higher price. Spending on drugs by hospitals grew by about 15% a year between 2012-13 and 2014-15. High-cost drugs and devices are often included as elements of specialised services. In 2015-16, an estimated £2.6 billion was spent on high-cost drugs for specialised services. In addition, pay inflation is increasing the overall wage bill for delivering all health services, and innovation and changing clinical standards may be increasing staff time per patient.

- **Changes to the specialised services portfolio.** New services, such as hand transplantation, have been added to the service portfolio by the Secretary of State for Health.

- **Changes to the way services are funded and specified.** For example, the boundary between specialised and non-specialised services is not clearly defined for many services. What is included in the costs of specialised services may vary geographically.

3 Investment in Hepatitis C medicines is likely to result in considerable cost-savings in the long term from reducing onward transmission of the disease.

Figure 8

Factors contributing to the rising costs of specialised services

Factor	Sub-factor	Example(s)
Activity growth	Growth in population and changes in demographics (such as ageing population).	Over the past 10 years, the population in England has grown by 0.8% a year on average but for those aged 65 and over it has grown by 1.8% a year on average.
	Demand for specialised services is growing faster than demand for other health services.	NHS England estimates that between 2009-10 and 2014-15, demand for health services increased by 2.7% a year. Using this data it expects demand for specialised services to increase by 4.4%, and for other services by 2.4%, each year until 2020-21.[1]
Cost per patient	Innovation in drugs and devices leads to new, previously unavailable treatments, or to more effective treatments replacing existing ones, often at a higher cost.	About 5% of cystic fibrosis patients are eligible for treatment with a new drug, Ivacaftor, which costs £182,000 a year per patient. In 2015-16, this treatment cost £55 million, with the cost expected to grow by about 9% in 2016-17.
		The percentage of radiotherapy patients, who received intensity modulated radiation therapy (an advanced form of radiotherapy which causes less damage to the tissue surrounding a tumour) increased from 10% (1,660) in April to June 2012 to 42% (7,387) in October to December 2015.[2] In 2016-17, the price for a course of treatment using 20 fractions with intensity modulated radiation therapy is around £4,100, compared with £3,100 with other complex but more conventional radiotherapy treatment.
	Pay inflation. In addition, innovation and clinical standards may be increasing staff time per patient.	Over the past five years, pay for employees in the NHS increased by about 1.2% each year. Pay accounts for around 60% of NHS costs. In 2016-17, a change in the national insurance arrangement will add an extra 1.8% to staff costs. From 2014-15, Monitor, which regulates the price of NHS services, increased the prices paid to acute hospitals for care by 0.3% to recognise the extra inputs required to meet new clinical standards which potentially add additional staff time per patient.
Specialised service portfolio	New services are introduced to the specialised portfolio.	From 2018, two proton beam therapy centres will go live, with an estimated set-up cost of £270–280 million and running costs of £50 million a year.
System management effects	More services are being concentrated in centres where the services are classified as specialised.	The number of neurosurgery outpatient appointments (classified as specialised) in 24 specialist neurology centres increased from 87,000 to 107,000 between 2012-13 and 2014-15 (an increase of 11% a year). The number of similar appointments in non-specialist centres reduced from 3,800 to 3,700 over the same period.
	Reimbursement is becoming more transparent.	Research suggests that the price (tariff) that NHS trusts receive for each unit of care for specialised services does not fully reflect the cost of providing these services (more than 10% under).[3] Monitor amended the top-up tariff for specialised services from 2013-14. The total cost of these top-ups is now around £300 million a year.

Notes

1 NHS England board paper, *Allocation of resources to NHS England and the commissioning sector for 2016/17 to 2020/21*, December 2015.

2 National Audit Office review of data provided by the National Clinical Analysis and Specialised Applications Team, hosted by the Clatterbridge Cancer Centre.

3 C Bojke, K Grašič and A Street, *The costs of specialised care*, Centre for Health Economics at the University of York, September 2014 and *How much should be paid for Prescribed Specialised Services?*, Centre for Health Economics at the University of York, October 2015.

Source: National Audit Office analysis of NHS England data and literature review

Part Two

The commissioning of specialised services by NHS England

2.1 This part of the report examines how NHS England has developed its capacity and capability to commission specialised services effectively, including managing the budget. It also looks at the impact this has had on the development of specialised services and providers' financial sustainability.

NHS England's development of specialised commissioning

Resources, strategy and delivery plan

2.2 NHS England took over responsibility for commissioning of 143 specialised services in April 2013. NHS England underestimated the scale of the challenge of commissioning these services. In addition, in its first year of operation, NHS England focused more on establishing clinical commissioning groups and less time was focused on its own commissioning functions.

2.3 Stakeholders told us that NHS England's specialised commissioning teams were significantly under-resourced to carry out their responsibilities during 2013-14 and 2014-15. In 2014-15, NHS England reviewed its resources for commissioning specialised services. It increased its budget from £20 million with 307 full-time equivalent staff, in 2014-15, to £38 million with 489 full-time equivalent staff, in 2015-16.

2.4 NHS England has not yet developed an overarching strategy for commissioning specialised services. NHS England staff told us that, given the level of resources it has had, its focus has been on establishing service baselines, sorting out information flows and managing transactions with providers with only limited focus on developing services and other strategic issues facing specialised services.[4] Through a strategic services review programme, NHS England has begun to examine strategic issues for a few high-priority service areas, including children's and adolescents' mental health services and secure mental health services. For some other service areas, NHS England has begun reshaping service delivery with the aim of improving delivery and patient outcomes, for example see **Box 1** overleaf.

4 Before 2013-14 no baseline information was collected consistently across the country.

Box 1

Supporting self-management to improve patient outcomes for patients with cystic fibrosis

Treatment outcomes for patients with cystic fibrosis are often dependent on patient behaviour, including adherence to treatment. For example, a high-cost inhaled therapy is now prescribed for patients to improve lung function. However, many patients do not fully adhere to the recommended treatment regime. This undermines the effectiveness of treatment, wastes resources and leads to avoidable hospital admissions. The NHS does not currently collect information on whether patients adhere to treatment regimes but research indicates that, across all preventative therapies, patients on average only use 36% of their treatment regimes.

In 2013-14, NHS England introduced a year-of-care tariff for cystic fibrosis. This aimed to encourage a more holistic approach to care along a patient's pathway and to give incentives for providers to support patients to manage their own treatment outside of hospitals. It also commissioned a pilot study, running between 2016 and 2020, to test the effectiveness of a new scheme to improve adherence to treatment regimes, using a computer chip to record when patients administer their treatment. Clinicians can use these data to help support patients in changing their behaviour and improving their adherence to treatment.

Source: National Audit Office review of documents provided by NHS England

2.5 NHS England has issued commissioning intentions for specialised services every year since 2013. These set out its priorities for the forthcoming year.[5] However, most trusts and clinical commissioning groups that responded to our surveys told us that NHS England's strategic intentions for specialised services were not clear and that this made it difficult to plan services in the long-term (**Figure 9**). For example:

- 65% of acute trusts and 73% of clinical commissioning groups disagreed, or strongly disagreed, with the statement that NHS England had clearly communicated its long-term plans for specialised commissioning;
- only 21% of acute trusts agreed, or strongly agreed, that their trust was clear about where specialised services sit within the NHS *Five Year Forward View*;[6] and
- 69% of acute trusts disagreed, or strongly disagreed, that NHS England's strategy for specialised commissioning helped them to plan for the long-term for the services they currently provide.

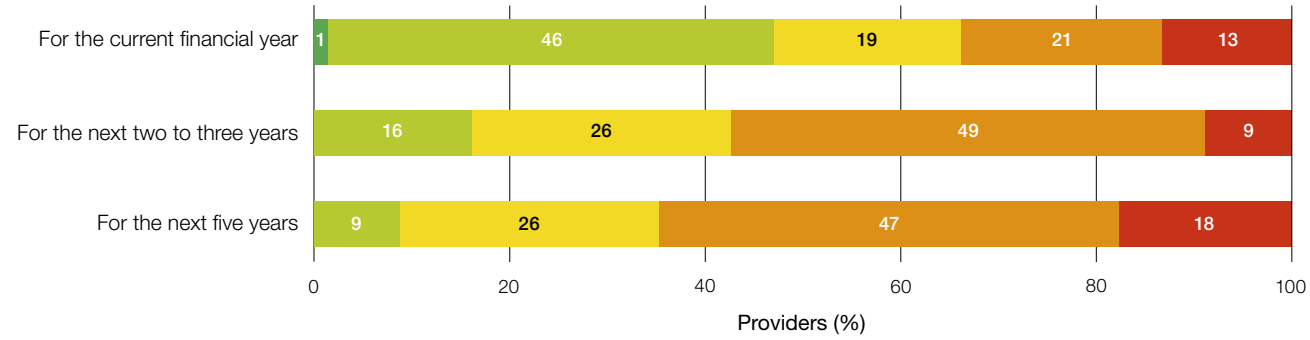
5 NHS England's commissioning intentions are available on its website at: www.england.nhs.uk/commissioning/spec-services/key-docs/

6 NHS England, Monitor, NHS Trust Development Authority, Care Quality Commission, Public Health England and Health Education England, *Five Year Forward View*, October 2014.

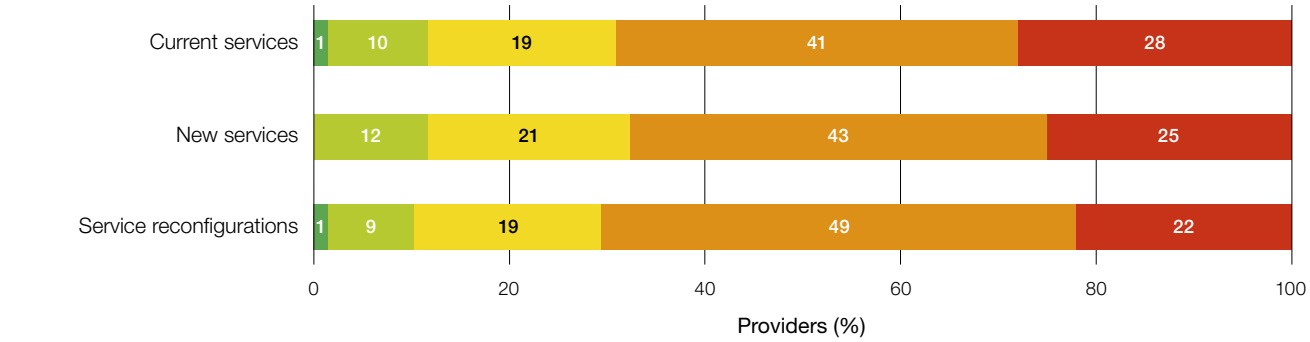
Figure 9

Stakeholder views on NHS England's strategy for the commissioning of specialised services

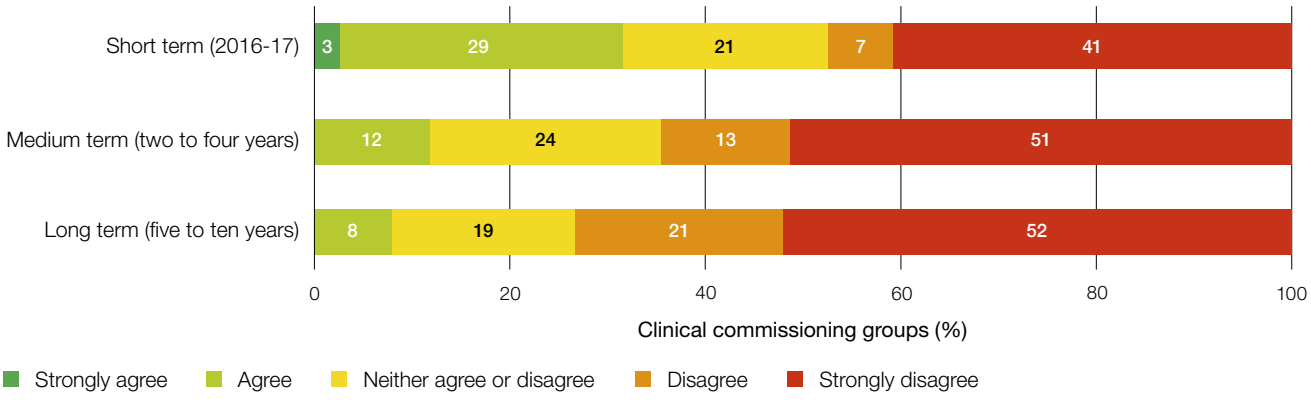
a) NHS England has clearly communicated its delivery plan or strategy for the commissioning of specialised services to your trust



b) NHS England's strategy on specialised commissioning supports your trust to make long-term plans for the future



c) NHS England has communicated a clear plan for the commissioning of specialised services to your clinical commissioning group



Notes

1 Survey results are based on 68 responses from acute NHS trusts, a response rate of 44% and 75 responses from clinical commissioning groups, a response rate of 36%.

2 Totals may not sum due to rounding.

Source: National Audit Office survey of NHS acute trusts and clinical commissioning groups

Governance

2.6 In line with its wider delivery structure, NHS England set up a 'matrix' arrangement for the commissioning of specialised services in 2013-14. Under this arrangement, reporting relationships were set up as a grid rather than in a traditional NHS hierarchy. Those responsible for the day-to-day commissioning of specialised services were members of multiple structures within NHS England, where lines of accountability and authority were not always aligned. This led to slow, opaque and often ineffective decision-making that may have contributed to the lack of progress in developing specialised commissioning during the first year. The structure was overhauled in 2014-15, when an interim taskforce was put in place. This estasblished seven work streams with a particular focus on financial control for 2014-15 and planning for the 2015-16 commissioning cycle. The taskforce arrangements ended in March 2015, when they became 'business as usual' and the Specialised Services Commissioning Committee was established (**Figure 10**).

2.7 NHS England's new governance arrangements for commissioning specialised services are complex and still being developed. Our previous reports have found that unstable and complex governance structures can have a negative effect on service delivery.[7] It is not clear whether the issues with the previous structure have been resolved as there is a lack of clarity about some lines of accountability and how decisions are made. For example:

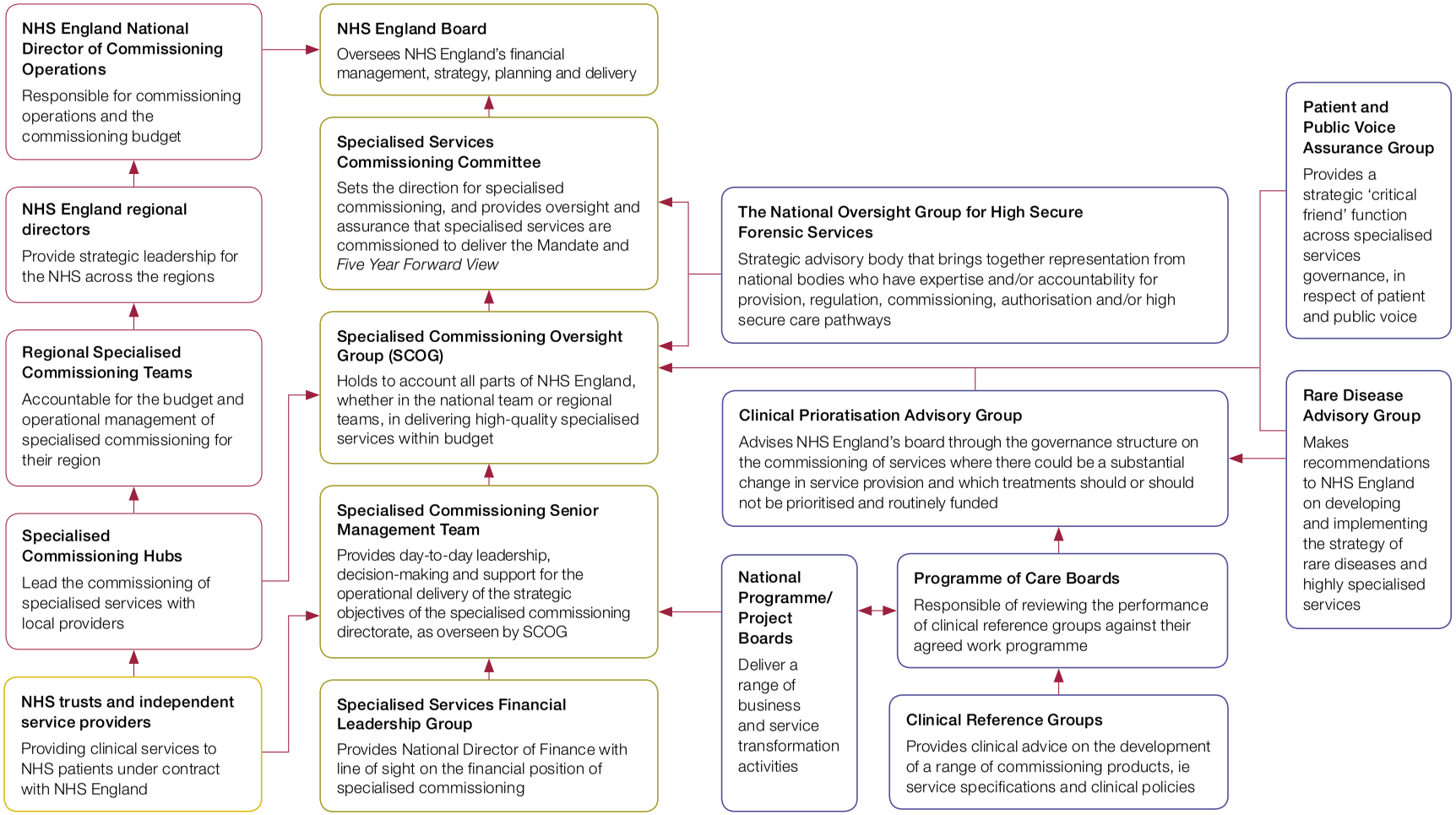
- members of some clinical reference groups and patient groups we spoke to were not sure how their advice is considered by NHS England;
- only 29% of acute trusts responding to our survey agreed, or strongly agreed, that the current governance arrangements were transparent and only 14% agreed, or strongly agreed, that NHS England's decision-making processes were consistent; and
- one of the Specialised Commissioning Oversight Group's roles is to provide assurance to the Specialised Services Commissioning Committee on the quality of commissioning of specialised services. However, there is a risk that it may not provide sufficient independent challenge to those who are responsible for the day-to-day commissioning of services, because nine of the 13 members of the group are also responsible for the operational delivery of commissioning services.

In April 2016, NHS England launched a 30-day consultation on a proposed method to support investment decisions in the commissioning of specialised services.

7 For example, Comptroller and Auditor General, *Police procurement*, Session 2012-13, HC 1046, National Audit Office, March 2013.

Figure 10

NHS England's management and governance structure for the commissioning of specialised services, 2015-16



Notes

1 The National Director of Specialised Commissioning is the chair of SCOG, a member of the Specialised Services Commissioning Committee and reports directly to the NHS England Board.

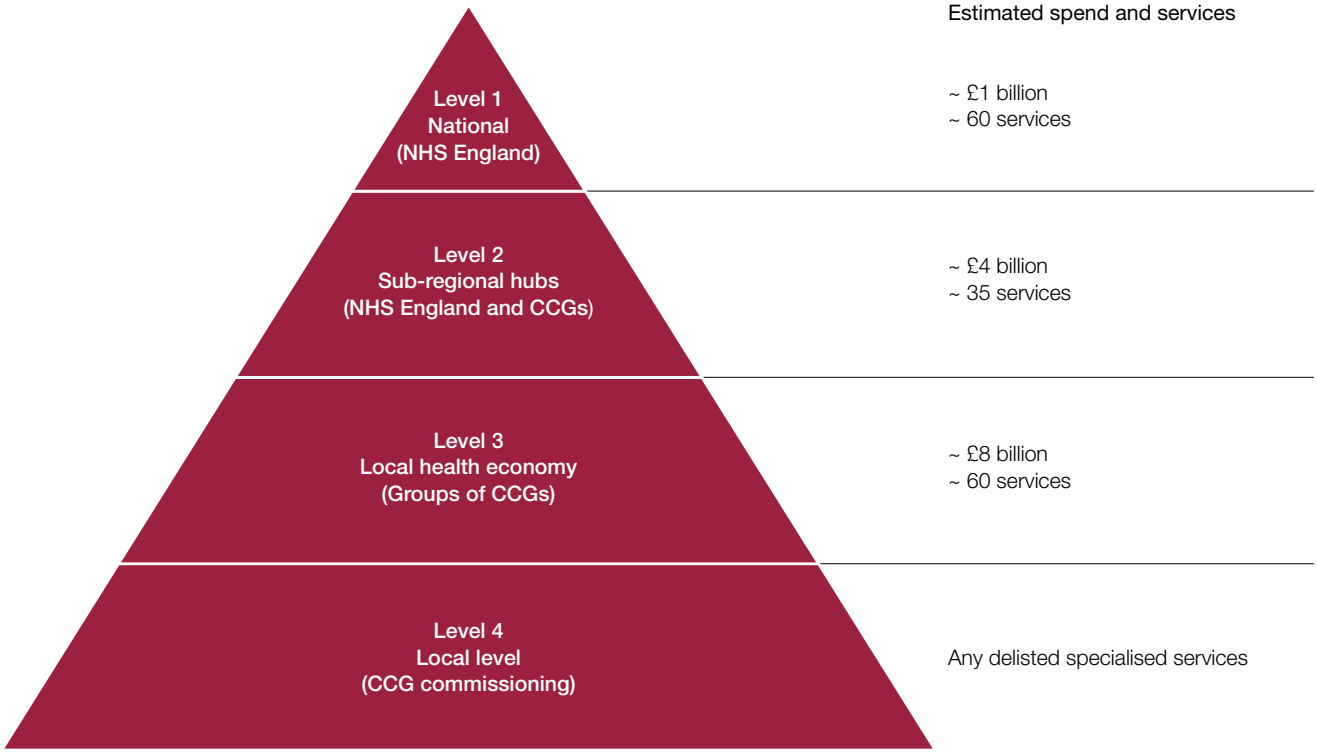
2 Regional specialised commissioning teams and hubs are supported by the Specialised Commissioning Senior Management Team in their day-to-day operations. They report to SCOG on their performance commissioning specialised services, but are held accountable by their regional directors for their specialised commissioning budgets.

Source: National Audit Office review of NHS England documents and interviews

Collaborative commissioning of specialised services

2.8 The NHS *Five Year Forward View* set out NHS England's intentions to progressively give clinical commissioning groups more influence over the total NHS budget for their local populations, including specialised services. There is consensus among most stakeholders that NHS England commissions too many specialised services. In addition, for patients with long-term conditions, specialised services often only cover part of their care pathway. As a result of the separation between the commissioning of specialised services and other NHS services, their care may be more disjointed. This can contribute to poor patient experiences (see paragraph 3.16). In addition to transferring the commissioning responsibilities for some specialised services to clinical commissioning groups, NHS England has also set out its intention to commission more specialised services collaboratively with clinical commissioning groups, with varying arrangements for different groups of the specialised services portfolio (**Figure 11**).[8]

Figure 11
Collaborative commissioning of specialised services between NHS England and clinical commissioning groups (CCGs)



Source: National Audit Office review of NHS England documents

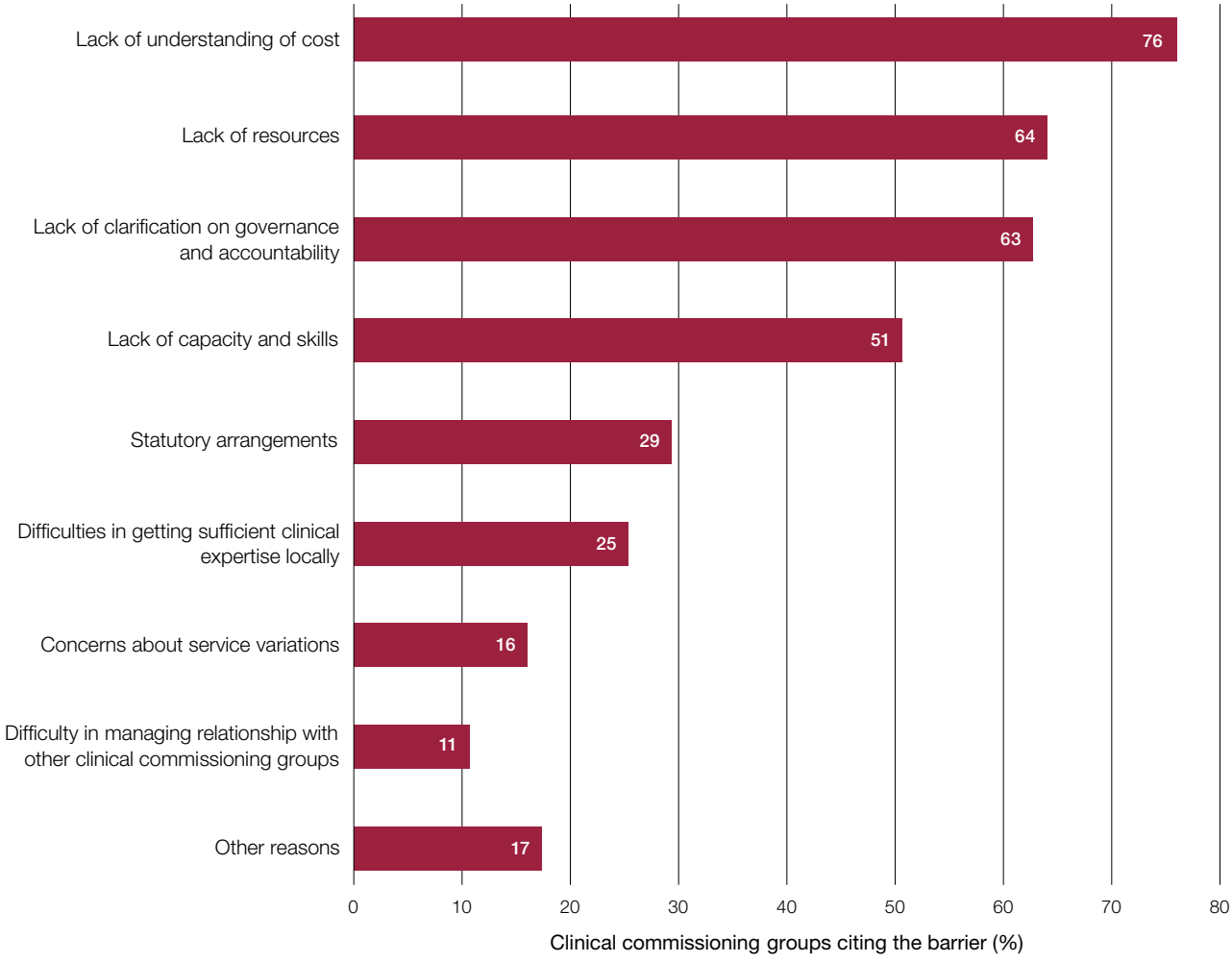
8 NHS England, *Developing a more collaborative approach to the commissioning of specialised services: guidance document*, March 2015.

2.9 While most of the clinical commissioning groups responding to our survey told us that they supported a joined-up approach to commissioning services,[9] only 37% felt that NHS England had clarified what it meant by collaborative commissioning. Clinical commissioning groups identified several barriers to collaborative commissioning (**Figure 12**), including a lack of clarity about cost, a lack of resources and a lack of clarification on governance and accountability.

Figure 12

Barriers to collaborative commissioning identified by clinical commissioning groups

Lack of understanding of cost was cited by 76% of clinical commissioning groups as a barrier to collaborative commissioning



Notes

1 Based on 75 responses from clinical commissioning groups, a response rate of 36%.

2 'Other reasons' include poor relationship with NHS England and opposition from patient groups.

Source: National Audit Office survey of clinical commissioning groups

9 72% of clinical commissioning groups responding to our survey agreed, or strongly agreed, that they supported a joined-up budgeting approach, and 92% agreed, or strongly agreed, that they supported a joined-up planning approach to collaborative commissioning.

Managing the budget for specialised services

2.10 Although the Secretary of State decides which services should be commissioned as specialised services, NHS England is responsible for setting the budget required to deliver these services. NHS England found it challenging to set this budget for 2013-14, because baseline figures submitted by local commissioners were inaccurate. Primary care trusts used to commission all acute services together and did not always have information specifically for specialised services. Despite increasing the budget during the year, from £12.23 billion (plus a further £0.24 billion for the costs of convergence) to £13.0 billion, NHS England overspent by £377 million (2.9% of its final budget for 2013-14), of which £31 million was due to the Cancer Drugs Fund.[10]

2.11 Since 2013-14, NHS England has undertaken work to improve its financial management of specialised services. This resulted in a reduced overspend for 2014-15 of £214 million (1.5% of the budget), £136 million of which was accounted for by the Cancer Drugs Fund. For the first ten months of 2015-16, NHS England reported an overspend on specialised services of £142 million, of which £110 million was for the Cancer Drugs Fund.[11]

2.12 NHS England also carried out modelling work to understand future pressures on cost. This work has helped to inform its budget allocation for the period 2016-17 to 2020-21. Modelling work is challenging because of gaps in data on baseline costs and activity for specialised services. In addition, the demand for highly specialised services can be volatile. NHS England has little control over the prices of, the demand for and supply of high-cost drugs, which account for about 20% of the costs of specialised services. NHS commissioners are legally required to fund drugs approved by the National Institute for Health and Care Excellence (NICE) and this makes it difficult for commissioners to secure these drugs at lower prices than those set by the pharmaceutical companies. NHS commissioners have discretion over whether or not to fund drugs that NICE has not reviewed or recommended. NICE assesses the clinical and cost-effectiveness of the new drugs that it appraises, but currently does not consider affordability. However, NICE is willing to allow flexibility in the implementation of its decisions under certain specified circumstances.[12]

10 NHS England includes the Cancer Drugs Fund when reporting its overall spend for specialised services. However, the Fund is managed separately from other specialised services. Excluding the Cancer Drugs Fund, NHS England overspent its budget for specialised services by 2.7% in 2013-14.

11 Excluding the Cancer Drugs Fund, NHS England overspent its budget for specialised services by 0.6% in 2014-15 and by 0.1% for the first ten months of 2015-16.

12 Commissioners are legally required to fund a drug within three months of its approval by NICE. However, under certain specified circumstances this period can be extended. For example, for Sofosbuvir, a drug to treat patients with Hepatitis C, in 2015 NICE agreed to: extend this period to seven months because NHS England required extra time to put in place the resources and clinical infrastructure required to begin to treat patients; and phased funding of the drug, recognising that it would take several years to treat all patients with chronic Hepatitis C within the current resource constraints. In 2015-16, NHS England provided access to the drugs for up to 5,000 patients and in 2016-17, it plans to fund up to 10,000 patients. An estimated 160,000 people in England are infected with Hepatitis C.

2.13 Despite these actions, NHS England's current information systems do not allow it to link all payment information to the actual services provided at national level. This is because of the different ways in which services are paid for and data are collected:

- For some services (accounting for about one-third of total expenditure), payments are based on the level of activity and unit price set at national level (national tariff). For these services, NHS England knows how much it spends on each service area at a national level.
- For the remaining services, there are no consistent national data available to allow NHS England to link payment to individual services. Although its local commissioning hubs collect data on how much they spend in each service area, these data are not collected consistently across the country. These services include high-cost drugs and devices, and services paid for using local prices agreed between NHS England local teams and service providers. In 2015-16, NHS England introduced standard reporting formats for these data and told us that consistent data would be collected by all providers from 2016-17. It also told us that, during 2016-17, it plans to introduce a national approach to the procurement of high-cost devices, which will aim to substantially reduce the variation that currently exists in the prices that individual trusts pay for these devices and then recharge to NHS England.
- NHS England local teams have often deviated from the national definitions for specialised services. This is because of difficulties in applying the national identification rules (see Figure 4, pages 18 and 19) for specialised services in some local settings. As a result, the actual services commissioned may vary from area to area. NHS England has already addressed many of these issues and told us that this practice will stop from 2017-18.

2.14 These data limitations mean that NHS England does not have a good understanding of what is causing the changes in cost across each specialised service area. In addition, these differences mean that price variations still exist. For example, in 2014-15 although the price paid for a kidney transplant with a live donor varied from £13,000 to £42,000 across the eight centres providing this service, it is not clear how much of the variation is justified because what is included in the price for each centre varies depending on the contract arrangements.

Contract management

2.15 National-level contracting of specialised services by NHS England has strengthened its position to influence providers compared with when these services were commissioned by a large number of local bodies. Our review of a sample of contractual arrangements between NHS England and providers showed that NHS England, and its local teams, are applying contract penalties to trusts for not meeting the contract agreement. Thirty-seven per cent of acute trusts responding to our survey said they had received financial penalties for not achieving service specifications for specialised services.

2.16 National-level contracting has also helped NHS England to get better value for money. For example, NHS England successfully used its bargaining power and secured an 18% reduction in prices, guaranteed for the duration of a ten-year contract, for PET-CT (positron emission tomography–computed tomography) scans currently in wide clincial use with an independent sector provider. However, this commercial capability is not always evident among NHS England's local commissioning teams. NHS England told us that performance has not been uniform in relation to contract and financial management across its local commissioning teams. Other stakeholders also expressed concerns about the capability of NHS England's local commissioning teams. For example, 57% of acute trusts responding to our survey raised concerns that these teams do not always have the commercial skills to effectively manage contracts with them.

2.17 NHS England's contracting process has not effectively supported providers to develop and improve services. Currently, with a few exceptions, NHS England limits the duration of contracts with providers to 12 months. Almost 84% of acute trusts responding to our survey reported that this does not enable them to plan services for the long-term. However, NHS England told us that, from 2016-17, it plans to increase the duration of contracts with selected providers to between two and five years. Contracts were often not signed before the in-service date, creating uncertainties for trusts in planning their services. For 2015-16, a larger proportion of acute trusts (87%) responding to our survey reported that they did not agree the contract with NHS England before the start of the financial year, compared with 2014-15 (73%) and 2013-14 (69%).

Controlling costs

2.18 NHS England and Monitor have sought to drive efficiencies by reducing the prices paid (tariff) for NHS services. For both 2013-14 and 2014-15, NHS England and Monitor required NHS trusts to deliver 4% efficiency savings, set within the price paid to NHS trusts for all NHS services including specialised services. In 2015-16, their proposed changes to the tariff were opposed by many providers. Two tariff arrangements ended up being used. The 'default tariff rollover' from 2014-15, which was chosen by 12% of trusts, continued to use 2014-15 prices without adjustment for inflation. Trusts choosing this tariff option no longer had access to a payment linked to service improvement, worth up to 2.5% of their income. The 'enhanced tariff offer', chosen by the remaining 88% of trusts, included a 3.5% efficiency saving.[13] In addition, NHS England and Monitor introduced a marginal rate rule for the trusts on the enhanced tariff offer in 2015-16. Under this rule, NHS England only paid trusts 70% of the tariff for specialised services above an agreed baseline activity level. Although this was intended to discourage providers from meeting shortfalls in efficiencies through increasing activity levels, in practice neither NHS England or providers have been able to control patient demand for these services.

13 In cash terms, for 2013-14 and 2014-15, the tariff paid to NHS trusts was reduced by 1.3% and 1.5% respectively after adjustment for inflation and top-ups for new clinical standards and quality improvement. For 2015-16, the reduction in cash terms for NHS trusts on the 'enhanced tariff offer' was 1.6%.

2.19 Evidence suggests that NHS providers, including trusts providing specialised services, are finding it increasingly difficult to remain financially sustainable with the current tariff arrangement. Eighty-nine per cent of acute trusts responding to our survey reported that their current income for specialised services did not fully cover the cost of delivering those services. Although trusts where a high proportion of their income comes from specialised services are still in a better financial position than those trusts with less income from specialised services, their financial position has deteriorated significantly over the past two years (**Figure 13** overleaf).

2.20 Trusts providing specialised services tend to be specialist, teaching or large district general hospitals. These trusts also have a higher level of income from sources other than NHS commissioners (NHS England and clinical commissioning groups).[14] Our analysis indicates that variations in the financial position of trusts is not linked to one factor, for example the proportion of income from specialised services, but is linked to a range of factors, including level of income from other sources and size of the trusts, that are difficult to disaggregate. NHS England told us that a new tariff arrangement (HRG4+), planned to be phased in from 2015-16, has been delayed to avoid destabilising the system in 2016-17, as this will be a challenging year. This tariff aims to support service redesign and better reflect clinical practices at a more granular level and in particular resource implications for complex care, many of which will be included as part of specialised services. Weaker financial positions and uncertainties over pricing and payment arrangements all potentially make it difficult for trusts to plan for future investment.

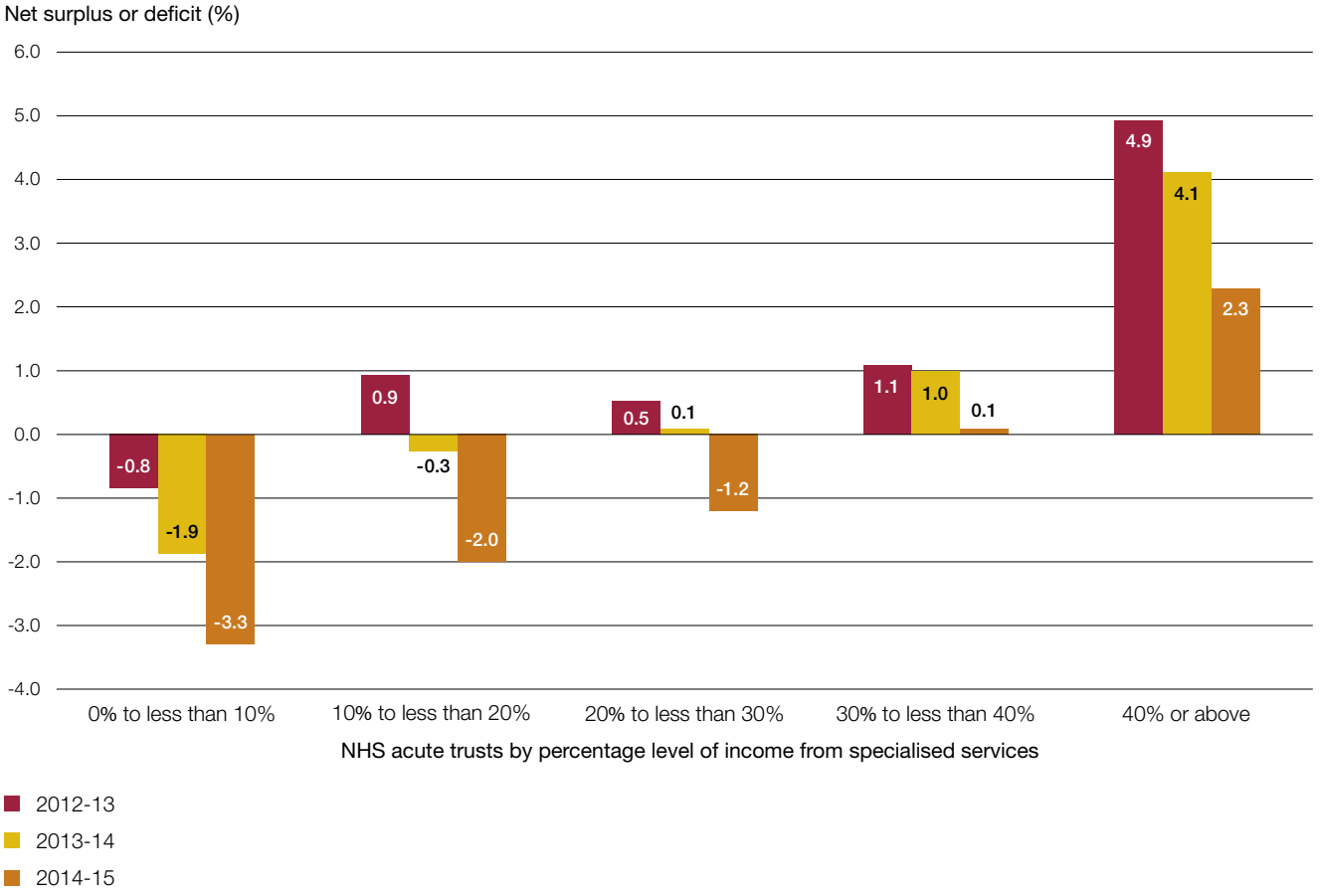
2.21 The financial challenges faced by NHS providers have been recognised in the tariff arrangements for 2016-17. Monitor and NHS England reduced the tariff efficiency requirement to 2%, and have suspended the marginal tariff for specialised services. In addition, the government has set up a £1.8 billion sustainability and transformation fund that aims to help trusts in financial difficulty to achieve financial balance.

14 Comptroller and Auditor General, *Sustainability and financial performance of acute hospital trusts*, HC 611, Session 2015-16, National Audit Office, December 2016.

Figure 13

Level of net margin by income level from specialised commissioning by NHS acute trusts, 2012-13 to 2014-15

The average surplus of acute trusts with 40% or more of their income from specialised services has decreased from 4.9% in 2012-13 to 2.3% in 2014-15



Note

1 Level of surplus or deficit is measured against operational income.

Source: National Audit Office analysis of NHS England data

Part Three

Patient outcomes and patient experiences

3.1 This part of the report examines patient access to specialised services, the quality of services provided, and patient outcomes and experiences. It looks at whether NHS England is achieving its objectives to reduce variations in access to services and improve patient outcomes.

3.2 NHS England is required to report annually to the Department of Health (the Department) on the progress it has made in reducing inequalities in health outcomes and in access to health services. It is also responsible for assuring the quality of the specialised services it commissions, which means that: services are delivered according to the best evidence as to what is clinically effective in improving a patient's health outcomes; care is delivered in a way that prevents avoidable harm and risks to patient safety; and the patient has as positive an experience as possible from the care.

Access to specialised services

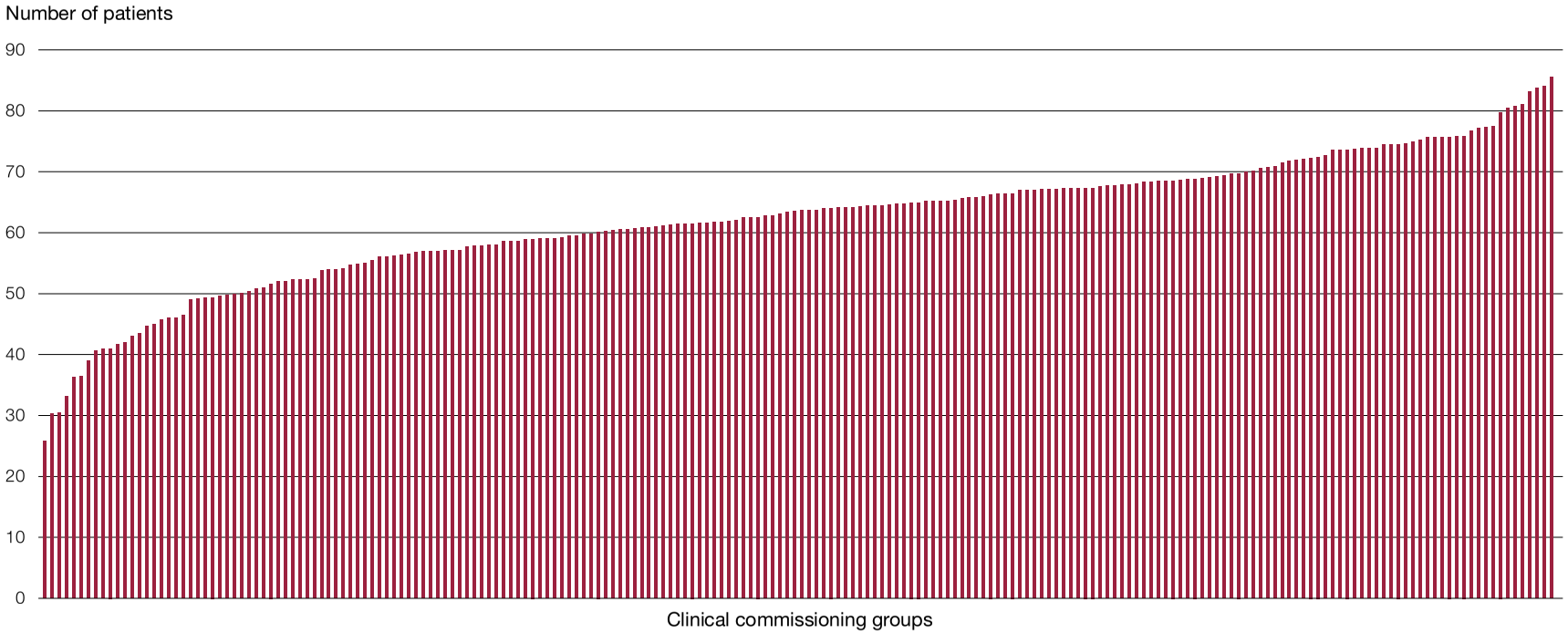
3.3 NHS England does not have consistent activity data for all specialised services (see paragraph 2.13), although it has made progress in developing national systems to collect this information. This means that NHS England has not been able to assess whether the level of access to specialised services has changed since it became responsible for commissioning these services, or whether inequalities in access to services have reduced.

3.4 Our analysis of a number of service areas indicates that activity levels over time vary by individual service: some have increased rapidly, even after adjusting for the level of need; some have remained static; and others have reduced. For some service areas where good data are available, large variations in access still exist across geographical areas. For example, in 2014-15 the number of cancer patients aged between 25 and 74 receiving chemotherapy per 100 new cancer cases varied from 42 to 77 across clinical commissioning groups, excluding the numbers in the lowest and highest 5% (**Figure 14** overleaf).

Figure 14

Number of cancer patients receiving chemotherapy treatment per 100 new cancer cases for all clinical commissioning groups, 2014-15

In 2014-15, the number of patients aged between 25 and 74 receiving chemotherapy treatment per 100 new cancer cases varied from 42 to 77 across clinical commissioning groups (excluding the numbers in the lowest and highest 5%)



Notes

1 All cancer types excluding non-melanoma skin cancers were included. The numbers of patients receiving chemotherapy treatment (the numerator) include all patients with a cancer diagnosis aged between 25 and 74 who received treatment in 2014-15 through NHS hospitals regardless of funding sources. The numbers of new cancer cases (the denominator) are the average number of newly diagnosed cancer patients over the three years 2011, 2012 and 2013 for all patients aged under 75. The numbers of new cancer cases for people aged under 25 is small (about 1% of all new cancer cases) and therefore have a minimal impact on the numbers calculated.

2 Many factors, including appropriate variations in clinical practices, variations in stages of diagnosis and patient fitness, can contribute to these variations in the level of access to chemotherapies.

Source: National Audit Office analysis of chemotherapy activity data provided by Public Health England and incidence data from the Cancer Commissioning Toolkit, produced by Public Health England

3.5 For treatments requested by patients, or their clinicians, that are not routinely available on the NHS, NHS England is responsible for assessing whether the treatment should be funded. NHS England has had limited resources to make timely decisions on these requests. As a result, some patients have been unable to access treatment (see **Box 2**). In spring 2015, NHS England identified a 'backlog' of some 150 decisions whether treatments should be funded, but could not put in place the capacity required to tackle this backlog until late 2015. Due to the delay, decisions on whether to fund these treatments have been postponed from February 2016 to summer 2016.

Box 2

Delays in accessing a new treatment for patients with tuberous sclerosis complex

The condition and the treatment	Tuberous sclerosis complex (TSC) is a life-threatening genetic disease that can lead to the growth of tumours throughout the body, for example tumours in the brain which can lead to epilepsy and learning disabilities. There are approximately 6,000 people in England with the condition. In 2011, an effective drug treatment (Everolimus) was licensed for TSC-associated tumours of the brain by the European Medicines Agency.
The role of NHS England	Everolimus is not routinely available on the NHS for TSC patients because NHS England has, to date, not made decisions on whether to routinely fund it in the absence of any NICE guidance on its use with TSC. NICE has not evaluated the drugs for use with TSC due to the small number of patients. To access drugs not approved by NICE, a patient would normally apply to NHS England through an individual funding request. However, if there are more than five patients requiring access to a drug for a particular condition, it has to go through NHS England's clinical prioritisation process.
What has happened	More than five patients met the prescribing criteria and so they could not apply individually for funding. Representatives of these patients approached NHS England from February 2013 onwards. NHS England has yet to decide whether to fund the drug for these patients, except for those risking significant harm within four months (where an 'urgent need' policy for access was made by NHS England following significant media coverage and political interest in the issue). In July 2015, NHS England informed the representatives that a commissioning decision would be made in 2015-16. However, this decision has yet to be made.

Source: National Audit Office analysis of NHS England data and literature review

3.6 Stakeholders have also raised concerns about the lack of transparency in NHS England's decision-making. For example, despite repeated requests from various stakeholders, NHS England has not made public any of its meeting notes or board papers for its decision-making bodies for specialised services until recently. In late 2015, it started publishing meeting minutes of the Patient and Public Voice Assurance Group, but meeting minutes of other decision-making bodies, such as the Specialised Commissioning Oversight Group, are not publically available. In some circumstances there may be a need for NHS England to weigh up the competing considerations between transparency and the need to drive commercially advantageous commissioning.

Quality of services

Service standards

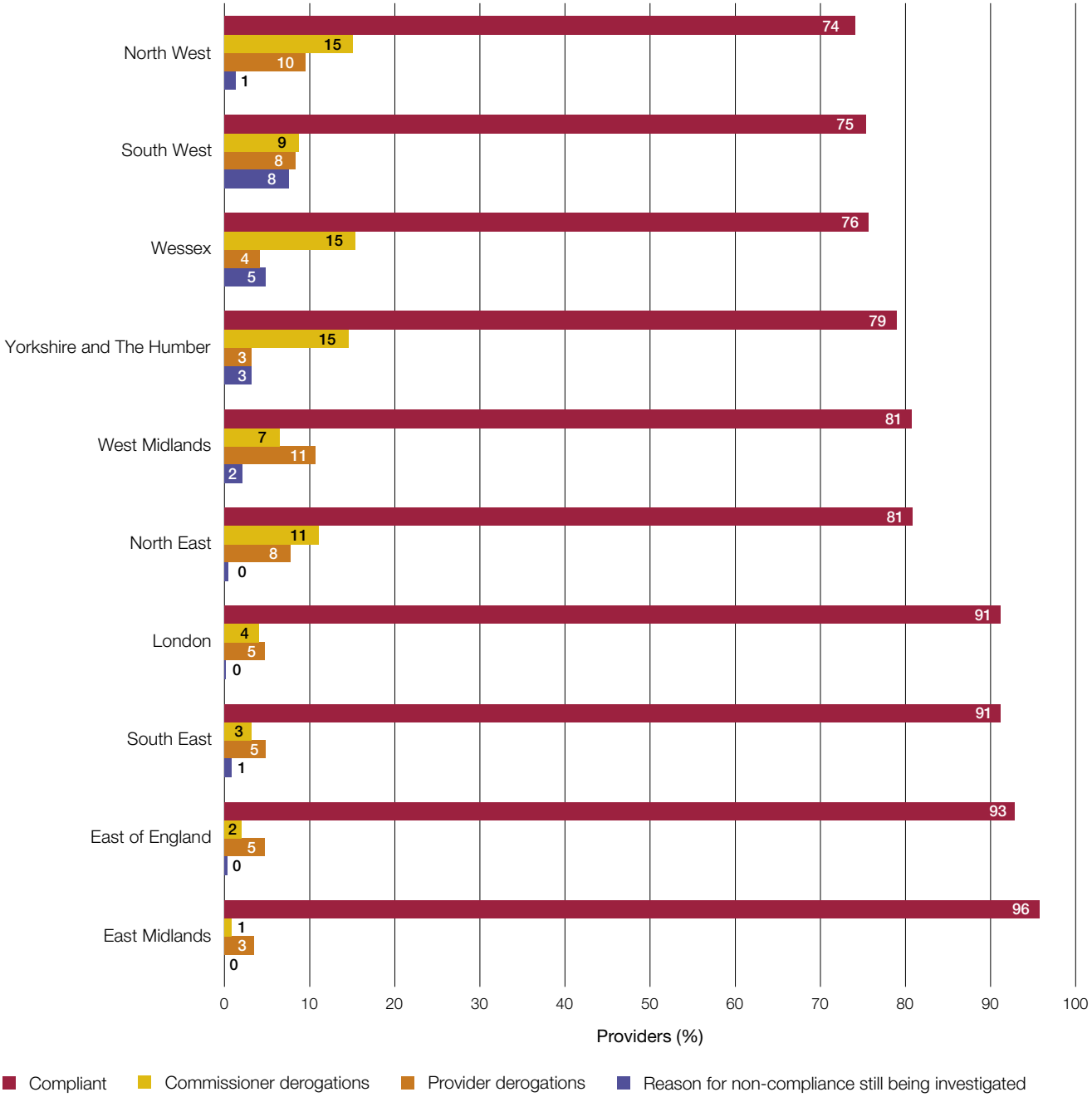
3.7 NHS England requires providers to meet the generic quality and safety standards set by the Care Quality Commission for all services. It has also sought to improve the quality and safety of specialised services by setting national service specifications and quality standards that all trusts are expected to meet. These specifications and standards, developed by NHS England's clinical advisory groups, reflect the best available clinical evidence or practice to improve patient safety and patient outcomes. They describe patient pathways and the main elements each service should cover, for example the mix of professionals that should be present in a cystic fibrosis specialist centre. NHS England has also collected data on how providers are meeting these specifications and standards. These data, for the first time, provided a basis to benchmark performance of specialised services on a national basis.

3.8 Where a service specification is not met, NHS England usually agrees a 'derogation' with the provider, which requires the provider (or the wider health system) to take action, but allows them to run the service while improvements are made or further planning is carried out. Derogations were introduced as a temporary measure, with the intention that all trusts should be fully compliant before April 2015. However, in February 2016 only 83% of services were compliant, up from 78% in September 2014, and 38% of providers had at least one provider derogation. Significant variations in compliance with these specifications exists both geographically (**Figure 15**) and between different service areas. Some stakeholders raised concerns that some specifications were developed without considering the impact on the resources required to meet them by trusts.

Figure 15

Level of compliance with national service specifications by commissioning hubs, February 2016

Compliance varies from 74% in the North West to 96% in the East Midlands



Notes

1 Provider derogations require the provider to take action but allows them to run the service while improvements are made or further planning is carried out. Commissioner derogations require action by the wider health system.

2 These data include derogations from both NHS hospitals and private service providers.

3 Totals may not sum due to rounding.

Source: National Audit Office analysis of NHS England data

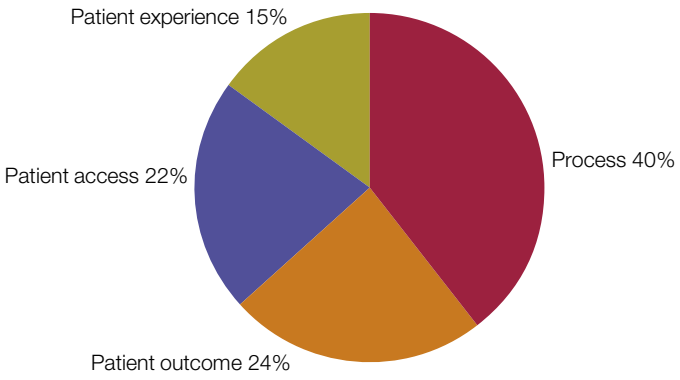
Quality assurance framework and quality dashboards

3.9 To provide assurance on the quality of care, NHS England developed a quality assurance framework for specialised services in 2014-15. The framework brings together a range of existing data already collected by various bodies across the NHS, for example clinical audits and peer reviews. It is also developing 'quality dashboards' for a number of service areas to make this information more accessible. These dashboards collect a range of information on clinical processes, clinical outcomes and compliance with national service specifications and standards for individual trusts (**Figure 16**). Although NHS England started developing these dashboards from 2013-14, the process was interrupted due to changes in the governance arrangements. By April 2016, dashboards had been developed for 41 service areas, but significant gaps in the data remain. For example, in 2015-16 only 77% of cystic fibrosis specialist centres were providing data for admitted patient care.

3.10 Currently, NHS England cannot benchmark one provider against another because trusts submit data for these dashboards in different formats. NHS England developed a dashboard 'portal', which became operational in April 2016. This will allow providers to submit data online in a common format.

Figure 16
Dashboard indicators for specialised services for ten service areas

Most quality dashboard indicators are process indicators



Notes

1 The ten service areas are: adult critical care; congenital heart disease; cystic fibrosis (adult and paediatric); haemophilia; human immunodeficiency virus (HIV); child and adolescent mental health services; paediatric oncology; positron emission tomography–computerised tomography (PET-CT); radiotherapy; and renal dialysis.

2 Patient outcome indicators include intermediate clinical outcome indicators.

3 Total may not sum due to rounding.

Source: National Audit Office analysis of NHS England dashboard data

Patient outcomes

3.11 NHS England currently reports progress on patient outcomes using the NHS outcomes framework, which provides national-level accountability for the outcomes the NHS delivers across a range of key indicators. Specialised services may contribute to the achievement of many of these outcomes but none can be solely attributed to specialised services. For example, there are four indicators for cancer patients, including the under-75 mortality rate for cancer and five-year survival rate for all cancers in children.

3.12 NHS England also intends to gain assurance on patient outcomes for individual specialised service areas using data collected through its quality dashboards. Most of the dashboard outcome indicators are process measures, with only a small proportion based on patient outcomes (Figure 16). For example, only two of the seven quality measures for HIV patients, and none of the four quality measures for cystic fibrosis patients, measure patient outcomes. Given these data limitations, NHS England is not able to monitor systematically how patient outcomes or inequalities in patient outcomes have changed since 2013.

Public engagement and patient experiences

3.13 NHS England has a number of mechanisms through which the public, patients and patient groups can feed into the development of specialised services:

- Since April 2013, patients and patient groups have been represented on the 74 clinical reference groups that develop clinical policies for specialised services on behalf of NHS England.
- In June 2014, NHS England established the Patient and Public Voice Assurance Group for specialised services, which aims to provide assurance that the voice of patients and the public has been captured and considered in the development of specialised services.
- NHS England also carries out public consultation for its main policies such as its proposed principles and processes for making investment decisions.

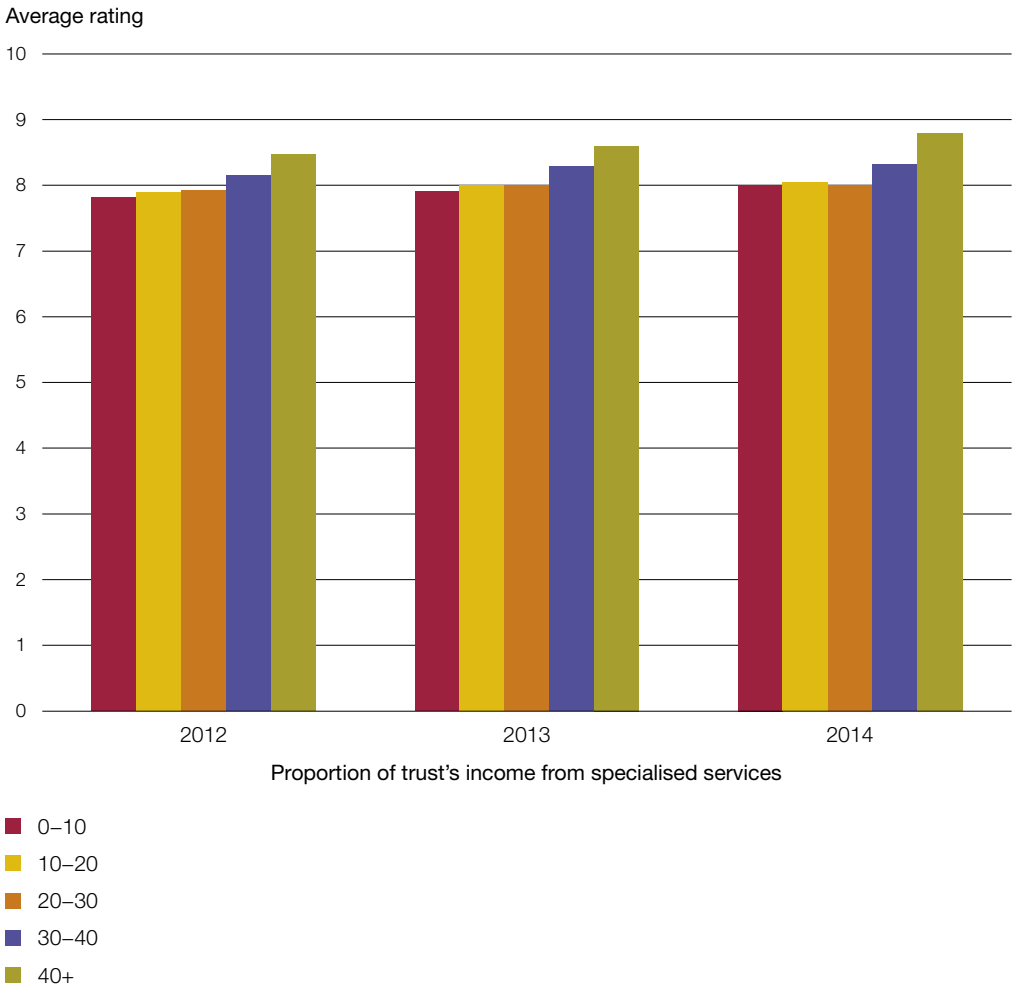
3.14 These arrangements have helped to incorporate, systematically, a patient perspective into the clinical policy-making process for specialised services. However, it is not clear to what extent patient concerns or views raised through these mechanisms have been reflected in the commissioning decisions made by NHS England (see paragraph 3.6). NHS England has begun to address these issues. For example, in late 2015 it started publishing meeting minutes of the Patient and Public Voice Assurance Group and appointed a number of lay chairs for its clinical advisory groups.

3.15 There is limited national evidence of how patients feel about their experiences of specialised services. In general terms, patients tend to be more satisfied with services from hospitals in which a higher proportion of their services are specialised services, in particular specialist hospitals (**Figure 17**).

Figure 17

Trends in patient survey results (mark out of 10)

Trusts that receive a higher proportion of their income from specialised commissioning consistently receive more favourable ratings



Source: National Audit Office analysis of Care Quality Commission survey data and NHS England data

3.16 Some patients, particularly those with long-term conditions, have found their care becoming more disjointed as a result of NHS England commissioning specialised services and clinical commissioning groups commissioning other services. This has led to gaps in service provision, for example see **Box 3**. NHS England has recognised these issues and plans to improve joined-up care and patient experience by commissioning more specialised services collaboratively with clinical commissioning groups (see paragraph 2.8).

Box 3

Gaps in service provision for people with motor neurone disease

Both NHS England and clinical commissioning groups commission adult specialist neurosciences services, depending on where the patient receives the service. The specification for these services states that all services for people with motor neurone disease should be commissioned as a specialised service. Despite assuming responsibility for the augmentative and alternative communication service (methods to supplement or replace speech or writing for motor neurone disease patients with impairments in speaking or writing) in April 2013, NHS England did not commission these services until 2015. During this time, some of the existing local arrangements were removed, leaving patients without any service. By 2015, these issues had been resolved.

Source: National Audit Office literature review and interviews with stakeholders

Appendix One

Types of specialised service

In 2015-16, there were 146 specialised services (**Figure 18**).

Figure 18
Types of specialised service

- Adult ataxia telangiectasia services
- Adult congenital heart disease services
- Adult highly specialist oesophageal gastric services in the form of gastro-electrical stimulation for patients with intractable gastroparesis
- Adult highly specialist pain management services
- Adult highly specialist respiratory services
- Adult highly specialist rheumatology services
- Adult secure mental health services
- Adult specialist cardiac services
- Adult specialist eating disorder services
- Adult specialist endocrinology services
- Adult specialist neurosciences services
- Adult specialist ophthalmology services
- Adult specialist orthopaedic services
- Adult specialist pulmonary hypertension services
- Adult specialist renal services
- Adult specialist services for patients infected with HIV
- Adult specialist vascular services
- Adult thoracic surgery services
- Alkaptonuria service
- Alström syndrome service
- Ataxia telangiectasia service for children
- Atypical haemolytic uraemic syndrome services
- Autoimmune paediatric gut syndromes service
- Autologous intestinal reconstruction service for adults
- Bardet-Biedl syndrome service
- Barth syndrome service
- Beckwith-Wiedemann syndrome with macroglossia service
- Behcet's syndrome service
- Bladder exstrophy service
- Blood and marrow transplantation services
- Bone conduction hearing implant services
- Breast radiotherapy injury rehabilitation service
- Child and adolescent mental health services – Tier 4
- Choriocarcinoma service
- Chronic pulmonary aspergillosis service
- Cleft lip and palate services
- Cochlear implantation services
- Complex childhood osteogenesis imperfecta service
- Complex Ehlers Danlos syndrome service
- Complex neurofibromatosis type 1 service
- Complex spinal surgery services
- Complex tracheal disease service
- Congenital hyperinsulinism service
- Craniofacial service
- Cryopyrin associated periodic syndrome service
- Cystic fibrosis services
- Diagnostic service for amyloidosis
- Diagnostic service for primary ciliary dyskinesia

Figure 18 *continued*
Types of specialised service

Diagnostic service for rare neuromuscular disorders

Encapsulating peritoneal sclerosis treatment service

Epidermolysis bullosa service

Extra corporeal membrane oxygenation service for adults

Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure

Ex-vivo partial nephrectomy service

Fetal medicine services

Gender identity development service for children and adolescents

Gender identity disorder services

Hand transplantation for adults

Heart and lung transplantation service

Highly specialist adult gynaecological surgery and urinary surgery services for women

Highly specialist adult urological surgery services for men

Highly specialist allergy services

Highly specialist dermatology services

Highly specialist metabolic disorder services

Highly specialist pain management services for children and young people

Highly specialist palliative care services for children and young people

Highly specialist services for adults with infectious diseases

Hyperbaric oxygen treatment services

Insulin-resistant diabetes service

Islet transplantation service

Liver transplantation service

Lymphangioleiomyomatosis service

Lysosomal storage disorder service

Major trauma services

McArdle's disease service

Mental health service for deaf children and adolescents

Neurofibromatosis type 2 service

Neuromyelitis optica service

Neuropsychiatry services

Ocular oncology service

Ophthalmic pathology service

Osteo-odonto-keratoprosthesis service for corneal blindness

Paediatric and perinatal post mortem services

Paediatric cardiac services

Paediatric intestinal pseudo-obstructive disorders service

Pancreas transplantation service

Paroxysmal nocturnal haemoglobinuria service

Positron Emission Tomography-Computed Tomography services

Primary ciliary dyskinesia management service

Primary malignant bone tumours service

Proton beam therapy service

Pseudomyxoma peritonei service

Pulmonary hypertension service for children

Pulmonary thromboendarterectomy service

Radiotherapy services

Rare mitochondrial disorders service

Reconstructive surgery service for adolescents with congenital malformation of the female genital tract

Retinoblastoma service

Secure forensic mental health service for young people

Severe acute porphyria service

Severe combined immunodeficiency and related disorders service

Severe intestinal failure service

Severe obsessive compulsive disorder and body dysmorphic disorder service

Small bowel transplantation service

Specialist burn care services

Specialist cancer services

Specialist cancer services for children and young people

Specialist colorectal surgery services

Specialist dentistry services for children and young people

Figure 18 *continued*
Types of specialised service

Specialist ear, nose and throat services for children and young people

Specialist endocrinology and diabetes services for children and young people

Specialist gastroenterology, hepatology and nutritional support services for children and young people

Specialist genetic services

Specialist gynaecology services for children and young people

Specialist haematology services for children and young people

Specialist haemoglobinopathy services

Specialist immunology services for adults with deficient immune systems

Specialist immunology services for children with deficient immune systems

Specialist mental health services for deaf adults

Specialist morbid obesity services

Specialist neonatal care services

Specialist neuroscience services for children and young people

Specialist ophthalmology services for children and young people

Specialist orthopaedic surgery services for children and young people

Specialist paediatric intensive care services

Specialist paediatric liver disease service

Specialist perinatal mental health services

Specialist plastic surgery services for children and young people

Specialist rehabilitation services for patients with highly complex needs

Specialist renal services for children and young people

Specialist respiratory services for children and young people

Specialist rheumatology services for children and young people

Specialist services for children and young people with infectious diseases

Specialist services for complex liver, biliary and pancreatic diseases in adults

Specialist services for haemophilia and other related bleeding disorders

Specialist services for severe personality disorder in adults

Specialist services to support patients with complex physical disabilities 'excluding wheelchair services'

Specialist surgery for children and young people

Specialist urology services for children and young people

Spinal cord injury services

Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders

Stickler syndrome diagnostic service

Vein of Galen malformation service

Veterans' post traumatic stress disorder programme

Wolfram syndrome service

Xeroderma pigmentosum service

Source: National Audit Office review of NHS England documents

Appendix Two

Our audit approach

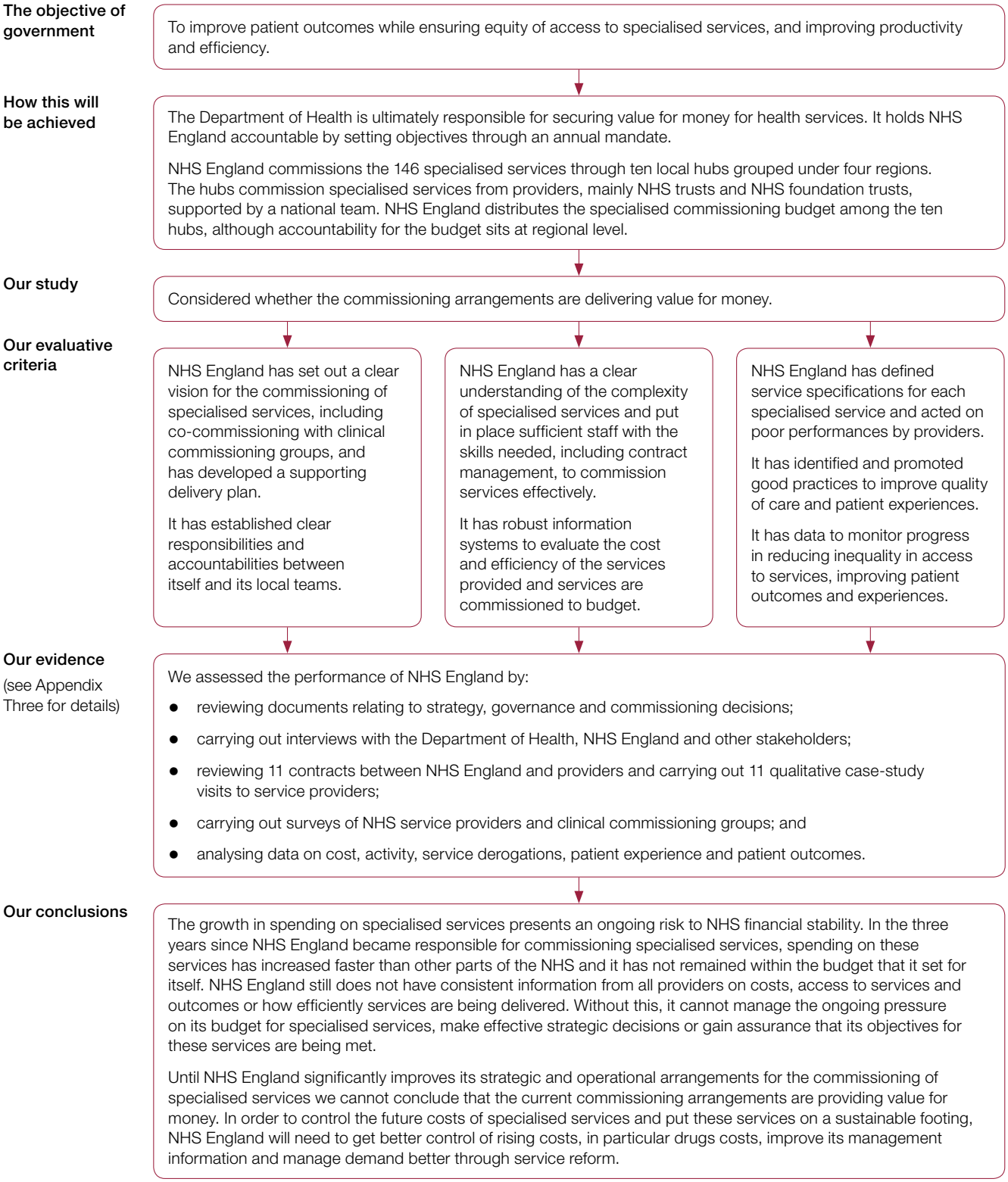
1 This report assesses whether NHS England is delivering value for money from its commissioning of specialised services and examines whether:

- NHS England has an overarching vision for the commissioning of specialised services and an effective delivery plan to achieve this vision;
- NHS England has the capacity and capability to commission specialised services effectively, including managing the budget; and
- NHS England is able to gain assurance that it is achieving its objectives to ensure equity of access to specialised services, improve patient outcomes, and improve productivity and efficiency.

2 We developed and applied an analytical framework with evaluative criteria that considered which performance and management arrangements would be optimal for achieving value for money. By 'optimal' we mean the most desirable possible, while acknowledging expressed or implied constraints. A constraint in this context is the number and variation of the services deemed to be specialised by the Secretary of State for Health.

3 Our audit approach is summarised in **Figure 19** overleaf. Our evidence base is described in Appendix Three.

Figure 19
Our audit approach



Appendix Three

Our evidence base

1 We reached our independent conclusions on the value for money of NHS England's commissioning of specialised services after analysing evidence we collected between October 2015 and February 2016. Our audit approach is outlined in Appendix Two.

2 **We interviewed staff from NHS England and other organisations.** We spoke to NHS England staff and others involved at all levels of commissioning specialised services including the Specialised Commissioning Oversight Group, the national team, regional teams, commissioning hubs, commissioning support units, clinical reference groups, National Programme of Care Boards and the Patient and Public Voice Assurance Group. We also spoke to other relevant stakeholders including the Department of Health, Monitor, NHS acute trusts, clinical commissioning groups, think tanks (for example, King's Fund, Centre for Health Economics, Nuffield Trust and the Health Foundation), bodies representing commissioners, service providers and patient interests (for example, NHS Clinical Commissioners, Specialised Healthcare Alliance, NHS Providers, Federation of Specialist Hospitals, Shelford Group and Healthwatch) and the Association of British Pharmaceutical Industries.

3 **We reviewed key documents.** These included: board papers; meeting notes; strategy; governance and planning documents that informed NHS England's commissioning approach; documents and online information from other bodies (for example, Healthwatch); and documents related to the providers and service areas in our case studies, including documents published by charities and other bodies representing patient interests.

4 **We analysed financial, outcome and activity data from NHS England, providers and other sources**. We analysed data from a range of sources to understand:

- how much money is being spent on specialised services;
- what is causing the increase in spending; and
- what is being achieved in terms of delivery against NHS England's objectives (patient access, patient outcomes, service quality and service efficiency).

Data sources included:

- NHS England's financial data, including expenditure on the commissioning of specialised services (by region and by service area, where available), expenditure on excluded drugs and devices, and the budget for specialised commissioning;
- acute trusts income from, and expenditure on, specialised services;
- patient outcome data (where available) from NHS England's quality dashboards, and from charities;
- data showing compliance with, and derogations from, service specifications provided by NHS England;
- inpatient activity data from hospital episode statistics (provided by the Health and Social Care Information Centre);
- NHS patient survey data including inpatient surveys by Care Quality Commission and cancer patient surveys;
- radiotherapy data provided by the National Clinical Analysis and Specialised Application Team and chemotherapy activity data by Public Health England; and
- other publicly available data from the Office for National Statistics, NHS reference costs data, and activity and prescription data published by the Health and Social Care Information Centre.

5 **We conducted two web-based surveys: of (1) all acute trusts in England and (2) all clinical commissioning groups in England.** Both surveys sought providers' or clinical commissioning groups' views and experiences on a range of issues, including the current scope of specialised services, NHS England's strategy for commissioning specialised services, its communication of that strategy, its capacity and governance arrangements and the impact of specialised commissioning on patient care. For the provider survey, we also asked questions on contracting arrangements, performance reporting, and tariff and reimbursement arrangements for specialised services. For the survey of clinical commissioning groups, we also sought their views on the development of collaborative commissioning.

6 Of the 154 acute trusts (excluding mental health trusts and those trusts with no contract with NHS England for specialised services), 68 responded to our survey, a response rate of 44%. Of the 209 clinical commissioning groups, 76 responded to our survey, a response rate of 36%. Results from our survey are available on our website at www.nao.org.uk/

7 **We undertook five case studies of specialised service areas.** We selected these service areas to better understand the challenges faced by NHS England in commissioning these services and the impact of commissioning on patient access to services, patient experience and patient outcomes. The five case study areas we selected were: cystic fibrosis; HIV; renal dialysis; neurological conditions (covering a number of specialised services) and the management of high-cost drugs (not considered as a specialised service).

8 **We undertook 11 case studies of acute trusts providing specialised services, including a review of their contracts with NHS England.** We selected providers of different sizes and types (small, medium and large acute trusts, teaching trusts, and specialist trusts) and geographic locations within England. The main aim of these case studies was to gain an understanding of how the commissioning approach taken by NHS England impacted on providers, and explore in more detail some of the issues raised by trusts through our survey. We also reviewed each trust's contract for specialised services with NHS England. When we conducted the contract review, we also spoke to the corresponding commissioning hubs and, in some cases, their local clinical commissioning groups.

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