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NHS England

Stakeholder engagement report to inform the developing scope of the five-year strategy for specialised services 2014/15 – 2018/19

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Stakeholder engagement report to inform the developing scope of the five-year strategy for specialised services

2014/15 to 2018/19

First published: Jan 2014

Prepared by the Specialised Services National Team, Medical Directorate, NHS England in partnership with the Specialised Healthcare Alliance

FOREWORD

Published in December 2013, *Everyone counts: Planning for patients 2014/15 to 2018/19* sets out proposals to make the NHS England vision and purpose "High quality care for all, now and for future generations" a reality. The foreword contains the following statement regarding the principles which underpin NHS England's work: "we prioritise patients in every decision we take, we listen and learn, we are evidence-based, we are open and transparent, we are inclusive, we strive for improvement.

NHS England has responsibility for directly commissioning specialised services. These are services which are provided for less common disorders and need to be concentrated in centres of excellence where the highest quality care can be provided – care that is clinically effective, safe and offers a positive experience for patients. It is important that these services are connected to research and teaching.

The principles of good specialised commissioning set out in the Carter Report of 2006[1] largely endure. While many of the report recommendations have been delivered, some remain outstanding or need to be updated to reflect more recent changes in the NHS in England. The most significant is that NHS England is now the sole commissioner of specialised services with a clear responsibility to show leadership in delivering the best outcomes and experience of care for patients.

In doing so, NHS England is keen to demonstrate its commitment to working in partnership with patients, the public, clinicians, patient organisations, providers, industry, academia and others, to develop its priorities in the coming years.

To support the delivery of this commitment, NHS England is working with the Specialised Healthcare Alliance and Rare Disease UK, as well as other key stakeholders, in order to facilitate the kind of multi-disciplinary working and engagement needed to ensure as diverse an audience as possible is involved in the strategy's development.

This report of the scope engagement event is the first product of this joint working and brings together in one place the views of a wide range of stakeholders, collated from both written submissions and from a major event held in London on 9 December 2013. Through these, we have heard from individuals and organisations from a range of backgrounds and with a variety of experience, drawn from across the country.

The final scope of the strategy will be subject to change over the coming months as we continue to engage with stakeholders at both a national and local level. It is only once this discussion phase is complete, that we will be able to determine a final version for inclusion in a draft five-year strategy, which will be the subject of public consultation in the spring. To find out how to get involved in this important work, please go to (http://www.england.nhs.uk/ourwork/commissioning/spec-services/five-year-strat/engagement/)

For now, we wish to thank all of those who have taken part in the initial scoping of the strategy. This input has been invaluable, and we hope that you will continue to engage with the development of the strategy in the months ahead.

James Palmer
Clinical Director Specialised Services
NHS England

John Murray
Director
Specialised Healthcare Alliance

EXECUTIVE SUMMARY

This report reflects feedback received from a broad range of stakeholders in proposing factors that might be included in the scope of the five-year strategy for specialised services, commencing in 2014/15. It includes a summary of the key points from the briefing materials that were provided to attendees at the scoping event and respondents to the written scoping exercise, as well as other feedback on the key themes.

This summary sets out the key considerations for the strategy's scope. Throughout the document, 'respondents' is used to refer to all who have provided feedback, whether in writing or at the scoping event. The detail of the strategy, taking account of this report, will be developed in the first few months of 2014.

Given the overlapping nature of the themes the key considerations need to be read as a whole.

General principles

- The strategy should ensure that patient and public involvement is prioritised throughout, including the need to ensure that hard-to-reach groups are included and that more formal opportunities are given for engagement with wider stakeholders
- The strategy should seek to define value both in terms for the patient and public and in economic terms and ensure the quality and continuous improvement of services over the next five years
- The strategy should be predicated on a transparent, ethical approach to decision-making built on evidence and evaluation
- The strategy should set out clear principles to guide any future reconfiguration
- The strategy should assess whether there is uncertainty or a lack of clarity on the scope of specialised services between the regulations, the Manual, service specifications and Identification Rules and, if necessary, recommend measures to address this
- The strategy should seek to provide clarity on the role and function of different aspects of the new commissioning arrangements, both in relation to the implementation of the strategy and for the system as a whole, to provide a robust guide for all stakeholders over the next five years.

Accountability

- The strategy should include a description of the governance processes in place to oversee the delivery of the strategy, including a description of what success looks like and who is responsible for measuring it
- The strategy should build upon NHS England commitments to increased openness and transparency and demonstrate how it would be developed across specialised services
- The strategy should set out standards for the provision of readily accessible information to patients and the public
- The strategy should consider how patients and the public are engaged in holding NHS England to account for the commissioning of specialised services.

Money

- The strategy should demonstrate how financial allocations for specialised services will be determined ensuring that they achieve the best outcomes for patients and value for money for taxpayers. It should also set out the financial planning required to ensure a clear understanding of activity trends, cost drivers, incentives and levers in the system
- The strategy should assess the clinical and economic evidence base for the consolidation of specialised services
- The strategy should set out a clear commitment to disinvest in interventions that have lower impact for patients and that a plan for the evaluation of existing interventions must be established. This disinvestment was deemed essential in order to allow re-investment in new services or innovations
- The strategy should assess the best approaches to improving the accuracy of costing and coding across the system, to ensure that it reflects the nature of the services and the intentions of commissioners. This should include developing recommendations for the implementation of the best approach at all levels in the system
- The strategy should make concrete recommendations on the future use of data and registries within specialised services as a means of tracking activity, costs and outcomes, ensuring that spending secures value
- The strategy should make recommendations on whether to adopt a programme budgeting approach to specialised services
- The strategy should develop clear and robust principles for the reinvestment of savings within specialised services where appropriate.

Integration

- The strategy should make an assessment of the current approach to integration and develop clear proposals, in partnership with other commissioners, for collaborative commissioning models between CCGs, NHS England and local authorities
- The strategy should seek to develop principles for ensuring that patient pathways motivate all parties to seek the best results for patients
- The strategy should look at how preventative care might be encouraged and linked more explicitly to its impact on specialised services
- The strategy should include full details of how strategic clinical networks, operational delivery networks and academic health science networks might support specialised services in future
- The strategy should promote the use of effective care plans and coordination for specialised care.

Quality and safety

- The strategy should provide clarity on how quality should be defined and measured
- The strategy should articulate how outcome measures can be used in assessing quality and should include clear commitments to ensure that they are used more widely

- The strategy should assess the merits of producing a best practice framework on data collection, registration and utilisation
- The strategy should set out recommendations for improving diagnosis and prevention
- The strategy should assess the benefits of national clinical databases (registries) and consider what information could be made publicly available
- The strategy should seek to describe clear guidance on quality and safety requirements for any potential reconfigurations within specialised services.

Innovation

- The strategy should include consideration of how NHS England encourages and manages innovation, including but not limited to products, technologies, service changes and clinical techniques
- The strategy should articulate a clear vision for how innovation is proactively encouraged by NHS England, tested and diffused through specialised commissioning. A clear vision for the processes for improving innovation in specialised services should be articulated
- The strategy should develop recommendations on how greater transparency will be provided on NHS England's processes and criteria for clinical prioritisation, including the assessment of innovation
- The strategy should provide clear commitments on how NHS England links with research for its specialised commissioning. This should include links with academic, clinical research and medical trials
- The strategy should define the future goals for NHS England's specialised commissioning links with other organisations relevant to innovation, such as NICE, the National Institute for Health Research, industry bodies and Academic Health Science Networks

BACKGROUND

In July 2013, NHS England launched its Call to Action in order to begin an open and honest discussion about the future shape of the health service. A major component of this work is the development of strategies for NHS England's direct commissioning, including a five-year strategy for specialised services.

In developing this strategy over the coming months, NHS England is committed to close engagement with all individuals and organisations with an interest in specialised services. This means working jointly with patients, patient organisations, clinicians, academia, providers, industry and the wider public at every stage of strategy development.

The five-year strategy for specialised services will be formed of two parts. The first is an overarching strategy document, the mission and vision for NHS England's commissioning of specialised services over the next five years. This will address overarching themes within specialised services, articulating a vision for the future shape of specialised care and describing principles to guide the steps needed to make this a reality.

Alongside this document, service-specific plans will also be produced, to provide clear priorities for each service in the years to come. NHS England will be inviting written submissions from any interested individual or organisation, seeking views on priorities for all of the services within specialised commissioning.

NHS England will engage with stakeholders at every stage of the development process for these two components of the strategy. For the articulation of the strategy's mission and vision, a series of 10 engagement events will be held in January and February 2014, led by each of the Area Teams with responsibility for specialised commissioning. These events seek to bring local patients, providers, clinicians, commissioners and others together to develop the detail of the strategy. They will be followed by a series of national Programme of Care led events, which will discuss the priorities for specific services and seek to align these with the overarching strategy commitments. A public consultation will also be held next spring on the draft strategy document, to enable further comments before it is finalised.

To begin this process, NHS England partnered with the Specialised Healthcare Alliance to run a thorough scoping exercise to assist the setting of the parameters of the five-year strategy. This included a major event, held in London on 9 December 2013, as well as a written submission process, including a briefing document to shape respondents' submissions.

This report summarises the feedback received from the event and the written submissions, to inform the scope for the strategy development work that will follow over the next few months. It is structured around the five themes, which were outlined at the event and in the written briefing document. Broadly speaking the themes brought out in both were endorsed but with valuable additions as a result of peoples' feedback.

GENERAL PRINCIPLES

Scoping recommendations:

Respondents welcomed the development of the five-year strategy for specialised services as an opportunity to maximise the effectiveness of the new commissioning arrangements. Key general principles were:

- The strategy should ensure that patient and public involvement is prioritised throughout, including the need to ensure that hard-to-reach groups are included and that more formal opportunities are given for engagement with wider stakeholders
- The strategy should seek to define value both in terms for the patient and public and in economic terms and ensure the quality and continuous improvement of services over the next five years
- The strategy should be predicated on a transparent, ethical approach to decision-making built on evidence and evaluation
- The strategy should set out clear principles to guide any future reconfiguration
- The strategy should assess whether there is uncertainty or a lack of clarity on the scope of specialised services between the regulations, the Manual, service specifications and Identification Rules and, if necessary, recommend measures to address this
- The strategy should seek to provide clarity on the role and function of different aspects of the new commissioning arrangements, both in relation to the implementation of the strategy and for the system as a whole, to provide a robust guide for all stakeholders over the next five years.

Overview of responses

Overall, respondents welcomed the decision by NHS England to develop a five-year strategy for specialised services. Some commented that it would have been helpful for a strategy to be developed at an earlier date but it was generally thought that it should help NHS England to deliver effective specialised services in a challenging environment.

> *"If it is implemented effectively then it will also help to facilitate some of the required transformational change and will enable the quality of specialised services to be significantly enhanced."* ***Birmingham Children's Hospital NHS Foundation Trust***

There was significant support for the strategy to reflect greater patient and public engagement in specialised services. It was thought that dedicated resources should be provided by NHS England to support this, especially to engage with harder to reach groups, including people with mental health problems, those with learning disabilities and children and young people. There was also a call to ensure geographical and social factors are taken into account when engaging with both professional and lay networks.

Respondents believed that a clear process for patient and public engagement should be established to support full engagement with relevant individuals across specialised services

and to set out how information about these services will be made clear and accessible. This process would help to ensure that patients knew the best way to raise concerns and contribute to service development. Certain charity representatives offered their assistance as a link to patients who could provide input in relevant areas.

> *"The strategy should set out the expectation that patients and the public be involved in the entirety of the specialised commissioning process, from policy development through implementation, monitoring and service improvement, and that the processes for this should facilitate patient involvement."* ***Asthma UK***

> *"NHS England has significantly greater scope than has previously been the case to bring stakeholders together to address multiple related policy and strategic challenges and to draw on the expertise of all stakeholders. Of particular relevance for our industry is the opportunity to work in partnership on research based initiatives directly with NHS England and the Specialised Services Clinical Reference Groups on research design, data collection and registries."* ***European Medicines Group***

> *"Clinical expertise is critical when making decisions about commissioning pathways, how care can best be integrated and what reconfiguration might look like as well as what measures should be used to assess quality, safety and patient outcomes."* ***Royal College of Surgeons***

Attendees at the event and written respondents generally agreed that delivering value should be a key principle for the strategy and that a clear definition of value should be included. Many respondents underlined that the focus of the strategy should be to promote world-class standards based on value, not levelling down service quality or through random cost-cutting.

> *"CTRad agrees it is necessary to ensure efficiency and value through all specialised commissioning – but encourages the strategy to be explicit that 'value' is more than cost alone. Evaluation of clinical outcomes is an important part of the assessment of value, and is therefore inextricably linked to clinical research."* ***National Cancer Research Institute clinical and translational radiotherapy research working group (CTRad)***

It was widely recognised that raising standards and ensuring sustainability within the current financial framework would require service changes and reconfigurations. Responses called for the strategy to set out general principles in relation to the reconfiguration of specialised services.

It was thought that, through setting out a clear approach to reconfiguration, the strategy might be able to help prevent a repetition of the problems encountered with the review of children's heart surgery. Most respondents thought that the strategy should look to achieve a balance between the need for patients to receive the best care and ensuring that a suitable geographical spread was achieved. Some asked for clarification on how specialist centres might be affected by enforced reconfigurations by special administrators.

> *"Decisions to move or aggregate specialist services should take into account the travel needs of the people with mobility needs."* ***Royal College of Nursing***

> *"Whilst we support the need to reorganise some services to ensure that patients can access high quality care, we would advise against co-opting specialist hospitals into reconfigurations unless the clearest clinical benefits for patients can be adduced."* ***Federation of Specialist Hospitals***

> *"If the shift of specialised services is moved towards one centre within the region, who is it who sets the Care Pathway… and – first and foremost – a low-risk/ high efficiency service for the patient? I think these can only be developed locally between centres and not by central propositions."* ***Dr Rainer Klocke, Consultant Rheumatologist/ Lead for Vasculitis, Dudley Group of Hospitals***

> *"[The] objective should be to spread most of the specialised services evenly across the country, with due regard to motorway and rail networks, access issues and the like, so that every part of the country is able to participate on an approximately equal basis."* ***Councillor John Illingworth, Leeds City Council***

Some respondents underlined the importance of an ethical approach to decision-making, to reflect the often difficult decisions that must be made in relation to what treatments should be made available. It was suggested that this approach should be underpinned by research. Links were also made to patient rights and the NHS Constitution and the need for the strategy to be aligned with these principles.

> *"Within the general principles of the strategy, we believe that research is a key aspect of specialised commissioning. This is already implicit in specialised commissioning, since it allows commissioning by evaluation for innovative services and treatments where there is typically less evidence available in these areas to support the development of a full commissioning policy. By extension, there should be a clear principle of developing specialised health services according to the evidence base."* ***British Heart Foundation***

> *"Whilst we are aware of the interim NHS England's Ethical Framework for Decision Making Policy which provides a basis it is important that the strategy clearly develops/sets out the revised Ethical Framework and sets out the mechanics of its implementation."* ***Association of the British Pharmaceutical Industry (ABPI)***

Certain respondents used the consultation as an opportunity to highlight gaps in the current CRGs. For example, Alder Hey Children's NHS Foundation Trust questioned whether the needs of children would be adequately addressed within the CRG and Programme of Care (POC) structures. Certain responses highlighted the importance of national leadership in ensuring strategic objectives are achieved and that CRGs should be appropriately resourced to support full implementation of service specifications.

ACCOUNTABILITY

Scoping recommendations:

- The strategy should include a description of the governance processes in place to oversee the delivery of the strategy, including a description of what success looks like and who is responsible for measuring it
- The strategy should build upon NHS England commitments to increased openness and transparency and demonstrate how it would be developed across specialised services
- The strategy should set out standards for the provision of readily accessible information to patients and the public

  The strategy should consider how patients and the public are engaged in holding NHS England to account for the commissioning of specialised services.

Overview

The initial briefing materials asked respondents whether the strategy should look at:

1. How quality or outcomes requirements are used as the benchmark for holding NHS England to account
2. How to improve transparency across NHS England's specialised commissioning
3. How accessible the information produced by NHS England is
4. How responsibility for different aspects of specialised commissioning is organised
5. How responsibility could be shared with patients and the public

Overview of responses

The issue of accountability and transparency appeared to be a priority for respondents judging by the weight of responses in this section. Respondents agreed that the strategy should set out plans to ensure appropriate accountability mechanisms are in place for patients and the public. It was thought that accountability should span across both value and quality of services and that getting accountability right within the system would be key to delivering high quality specialised services.

Some respondents felt that the success of specialised services would be dependent on ensuring a greater understanding of where responsibility lies and much more transparency in processes.

> *"Across many patient pathways in which there are complex relationships between prevention treatment and care the post April 2013 system no longer has any single line of responsibility or accountability. This is causing confusion and has the potential to undermine existing high quality care when the lines of accountability are so difficult to identify."* ***British HIV Association***

> *"The strategy should set out to demonstrate the highest standards of accountability in relation to all legitimate stakeholders, including industry. Otherwise, delivery of the ambitions for closer partnership expressed notably in Innovation, Health and*

> *Wealth will continue to founder."* ***Gilead***

Many responses underlined the need for the strategy to outline plans for better communication and transparency of NHS England processes and decision-making. Respondents asked that the strategy set out transparent processes, including timelines for review, re-review and decision-making for service specifications and policies. Some respondents called for these processes to be developed in partnership with consultees, others suggested that the processes used by NICE in developing clinical guidelines might be followed. Given the number of CRGs, transparency in processes will help to support wider engagement in the development of service specifications.

> *"The College feels that clinicians, patients and the public would benefit from a better understanding of how decisions are made about which services should be commissioned nationally or locally as well as how commissioning policies are developed."* ***Royal College of Surgeons***

Representatives from industry were particularly keen to ensure clarity in processes, to support them in introducing new treatments into the NHS. A number of respondents called for clarity in processes for making treatments available that fall outside the standard NICE technology appraisal process. Certain respondents highlighted the need for appeal processes for these decisions.

> *"Provide details of a clear, transparent and robust process by which new treatments are included and funded under national commissioning policies to ensure greater certainty for patients, clinicians and companies alike."* ***Actelion***

It was also thought that the strategy should set out how transparency could be applied to the decision-making process, including what evidence decisions are based on and what groups and individuals may have been involved in the final decision.

> *"We also believe that decisions on commissioning and related business, such as quality markers and measurements must be more transparent. How decisions are arrived at is not at all transparent presently. Perhaps adopting a similar approach to the methods which NICE use to publish their meeting minutes and declare conflicts of interest would be appropriate."* ***British Kidney Patient Association***

Respondents set out that once a decision is met, there should be clear communication of agreed policies or service specifications, both within the NHS and to external stakeholders. A number of respondents cited problems that have occurred in relation to the roll-out of national service specifications on a local level by Area Teams. It was suggested that the strategy could set out plans for toolkits or action plans to demonstrate how policies should be rolled out. This would set out how levers and incentives can be applied, what accountability measures are required to align local implementation with national policy and how NHS England will be held to account for delivering against it.

Respondents thought that the strategy might be able to support greater clarity on what is defined as a specialised service and what elements of care would be commissioned by NHS England, CCGs or local authorities. It was generally felt that the Manual alone is not clear enough. This clarity would support greater accountability as it would ensure that people are

aware of who has ultimate responsibility in a given area. It was recognised that accountability should be sought at all levels to reflect the different areas of responsibility.

Within specialised services, respondents requested that the strategy set out a system diagram for the commissioning, including CRGs and how they link in with the national decision-making and local area team implementation. There were also calls to ensure accountability of providers to deliver on the services commissioned from them.

> *"The strategy should include clarity where there is a NHS England/CCG funding split on who is ultimately responsible to ensure accountability. The strategy should also include how NHS England will address this problem which is at odds with the standardisation of NHS England with a commitment to achieve equitable patient access across England."* ***Medtronic***

> *"It is important that the strategy clarifies the roles and responsibilities of the various groups within the existing commissioning structure and how they inter relate. It is currently not clear where decisions which take into account both service quality and the current constrained financial environment should be taken."* ***Great Ormond Street Hospital NHS Foundation Trust***

> *"A clearer demonstration of how NHS England responds to and assesses the advice of the CRGs should also be included to encourage long term clinical commitment to, and confidence in, the system."* ***Specialist Orthopaedic Alliance***

Some respondents questioned whether internal accountability mechanisms within specialised commissioning in NHS England were sufficient. Respondents also called for the strategy to set out how accountability sits between Monitor and the Care Quality Commission (CQC). Some thought that the role of health overview and scrutiny committees (HOSCs) in holding services to account should be considered, including the potential for groups of HOSCs to consider particular issues, ensuring sufficient reference is made to local people's needs.

> *"Local authority health scrutiny has had the role of holding health service commissioners and providers to account for many years. The role of Overview and Scrutiny Committees should be viewed constructively".* ***Cllr Lisa Mulherin, Leeds City Council, Chair, Leeds Health & Wellbeing Board***

Respondents recognised the role of external stakeholders such as patient groups to hold NHS England to account in its commissioning of specialised services. This could be supported by more avenues for inviting patient feedback such as through social media.

> *"There is a need for a usable mechanism through which to report problem/gaps in commissioning of specialised activities identified by patients/patient groups if they don't have input into CRGs. This would ensure that any issues occurring as a result of unclear commissioning of services can be directly fed back to specialised commissioners so that these can be addressed."* ***Muscular Dystrophy Campaign***

There was recognition that outcomes need to be established for specialised services, in line with the NHS Outcomes Framework. In turn, data need to be better developed to support measurement against them. Respondents supported the use of quality dashboards or traffic

light ratings for different services. This could support patient choice but would also help commissioners to monitor how service specifications were being implemented on the ground.

It was thought that the strategy could support the availability of data at each level of responsibility to support better accountability. This could include CRGs, strategic clinical networks and providers. Respondents suggested that the provision of data is the only way that NHS England will be able to monitor the services provided to different types of people across the country. Certain respondents highlighted that lessons could be learnt from initiatives such as the Cancer Patient Experience Survey and systems to monitor the use of chemotherapy within England.

> *"Quality outcomes should stem from the implementation of robust service specifications. Currently, there are a significant number of derogations in place. The strategy should underline the need for transparency as to when these exceptions will be addressed, particularly where there is failure to comply within the agreed timelines."* ***Federation of Specialist Hospitals***

Respondents also stated that the strategy should support wider benchmarking of services with other countries.

> "We believe NHS England should be accountable for ensuring specialised services in the UK are benchmarked and measured against similarly developed European countries, so that care and outcomes in the UK are readily comparable to the rest of Europe." ***GSK***

MONEY

Scoping recommendations:

- The strategy should demonstrate how financial allocations for specialised services will be determined ensuring that they achieve the best outcomes for patients and value for money for taxpayers. It should also set out the financial planning required to ensure a clear understanding of activity trends, cost drivers, incentives and levers in the system
- The strategy should assess the clinical and economic evidence base for the consolidation of specialised services
- The strategy should set out a clear commitment to disinvest in interventions that have lower impact for patients and that a plan for the evaluation of existing interventions must be established. This disinvestment was deemed essential in order to allow re-investment in new services or innovations
- The strategy should assess the best approaches to improving the accuracy of costing and coding across the system, to ensure that it reflects the nature of the services and the intentions of commissioners. This should include developing recommendations for the implementation of the best approach at all levels in the system
- The strategy should make concrete recommendations on the future use of data and registries within specialised services as a means of tracking activity, costs and outcomes, ensuring that spending secures value
- The strategy should make recommendations on whether to adopt a programme budgeting approach to specialised services
- The strategy should develop clear and robust principles for the reinvestment of savings within specialised services where appropriate.

Overview

The initial briefing materials asked respondents whether the strategy should look at:

1. How money flows through specialised services
2. How well defined specialised services are for the purpose of identifying responsible commissioners
3. How well aligned specialised service planning is with the payment system
4. How financial support links with commissioning activity and where this should be used further
5. How well the drivers of cost in specialised services are understood.

Respondents agreed with the areas covered in the briefing materials on the whole.

A number of concerns were raised in relation to the current financial situation within specialised services and how a strategy might be able to prevent future overspends or uncertainty, without impacting negatively on the services provided.

> *"No one knows the cost of the separate elements of a patient pathway and what all the different components included in block contracts are. This is causing difficulties for commissioners."* ***Macmillan Cancer Support***

> *"The financial allocations are not yet right, leaving providers and patients in an uncertain position."* ***City Hospitals Sunderland NHS Foundation Trust***

> *"As the briefing document identifies, it is important to have a consistent payment system to ensure stability for service providers to plan ahead and provide high quality services… In the design of payment systems for specialised services, payments based on results need to be equitable and based on an understanding of people's needs, not current service configurations."* ***Turning Point***

Many respondents felt that the strategy should set out the flow of money and how it is used to pay for treatments and services. Greater clarity in service specifications and the delivery of the Manual were hoped to lead to more informed discussions about the financial split between CCG and NHS England commissioned care.

Some respondents also underlined the current geographical inequality in terms of spend on specialised services and asked whether a strategy might be able to address this. Comments were also made on the importance of distinguishing the specialised and non-specialised budgets in local contexts.

> *"With specialised commissioning budgets managed independently from local commissioning budgets, there is a risk of cost and blame-shunting between the different parts of the system. Under the 'accountability' theme, it will be important to look at how NHS England and local commissioners work together to manage the interfaces between specialised and non-specialised services."* ***NHS Confederation***

Respondents also discussed existing anomalies or perverse incentives that they felt should be considered as part of the strategy.

One issue raised was the challenge when a particular intervention may not financially benefit the group that instigates that process, for example a public health intervention from a local authority would be unlikely to benefit the authority's finances directly, but could reduce demand at CCG and NHS England commissioning level. This disconnect was thought to risk perverse incentives from the perspective of patient care. Some respondents thought that care planning and a year of care model could be reflected in the tariff for specialised services to address some of these issues.

Linked to this, a number of respondents highlighted that much new pharmaceutical and medical technology innovation comes from specialised services, while savings may be enjoyed elsewhere. Some believed that there was a need for money to move across organisational boundaries, between NHS England, CCGs and local authorities in order to support improved outcomes. Certainly there was a feeling that the roll-out of innovation should not be delayed due to incorrect allocation of resources within the NHS.

Many respondents highlighted the current lack of awareness of the full costs of specialised services. There was a recognition that the strategy should clearly set out the need for proper pricing and costing mechanisms. This could include plans to move to the national tariff, where appropriate.

Some respondents highlighted the current lack of clarity on how services will be costed and many more highlighted that issues with coding make it very difficult to understand how certain services are priced. Issues were highlighted in relation to the classification of rare diseases and how this is reflected in costs for different services. Certain respondents underlined the need for this cost-adjustment to be undertaken in the context of the NHS England and Monitor payment development system.

Specialist providers called for active engagement with them in relation to the cost of services, given their direct understanding of key costs involved. For example, providers felt that current reference costs do not adequately address specialised services or infrastructure requirements.

> *"The strategy should also reflect how NHS England will approach ensuring that specialised services are accurately clinically coded and therefore the appropriateness of non-tariff arrangements. Having consistency in the recording of specialised activity will form the basis for a wider review concerning the costs of delivering these services and how national tariff payment systems best support this."* ***Queen Victoria Hospital NHS Foundation Trust***

> *"If the model is to allocate resources directly to the Hub to manage this would involve significant additional transaction costs as Hub providers would be required to manage the finance/activity and quality performance of the spoke providers and therefore set up their own commissioning units which is an inefficient use of NHS resources to duplicate this function in providers."* ***Royal National Hospital for Rheumatic Diseases***

> *"It is unlikely that any single organisation will be able to deliver all specialised services or indeed a single service over a large geographical area. In many cases there will need to be more than one point of delivery and the expertise may be spread across trusts."* ***Pelvic Pain Support Network***

Responses included a discussion on how a strategy might be able to support the NHS to deliver improved outcomes, using the same, finite resources. This would include looking at financial models and incentives to drive financial planning. The strategy could, for example, introduce plans to develop a cost optimal model of care for each service to ensure value for money. These models should be focused on outcomes, not inputs. It was thought that savings could be secured by better use of available expertise, for example the use of multi-disciplinary teams to reduce costs and unnecessary spend.

Some respondents stated that the strategy should set out a clear commitment to disinvest in interventions that have lower impact for patients and that a plan for the evaluation of existing interventions must be established. This disinvestment was deemed essential in order to allow re-investment in new services or innovations.

It was also recognised that in order to reduce costs, the strategy may need to set out how the number of providers could be reduced. This might address the fixed costs associated with delivering a particular service.

> *"There will be difficulties in achieving efficiencies in services with a high fixed cost base unless there is rationalisation of specialist providers coupled with use of technology and appropriately funded network structures."* ***Great Ormond Street***

NHS Foundation Trust

Many respondents recognised that short term contracts and annual budgets make it difficult to implement long term strategic plans. Respondents suggested that the strategy could set out plans for greater engagement with providers and suppliers to support better financial horizon scanning.

"Specialised hospitals need to be involved in active discussions with NHS England regarding future demand projections so that capacity can be planned. As fewer centres offer a wider range of specialised services this can be a complex picture and sufficient time and funding needs to be given." ***Guy's and St Thomas' NHS Foundation Trust***

"Regarding future budget planning for specialised services, it may be helpful to consider including a process of engagement with providers and suppliers (including pharmaceutical companies), which would go above and beyond services such as Pharmascan to ensure genuine partnership working to plan future demand." ***Shire***

"Both capital costs and on-going expenditure on specialised services must be considered as part of the strategy. Some services, such as radiotherapy, require capital expenditure in order to replace or update machinery. Therefore plans must ensure specialised services can budget for this type of expenditure." ***Cancer Research UK***

Transparency was also highlighted as a particular issue, including the need for robust cost collection and clearly defined services for costing.

INTEGRATION

Scoping recommendations:

- The strategy should make an assessment of the current approach to integration and develop clear proposals, in partnership with other commissioners, for collaborative commissioning models between CCGs, NHS England and local authorities
- The strategy should seek to develop principles for ensuring that patient pathways motivate all parties to seek the best results for patients
- The strategy should look at how preventative care might be encouraged and linked more explicitly to its impact on specialised services
- The strategy should include full details of how strategic clinical networks, operational delivery networks and academic health science networks might support specialised services in future
- The strategy should promote the use of effective care plans and coordination for specialised care.

Overview

The initial briefing materials asked respondents whether the strategy should look at:

1. How well integration works in practice;
2. How closer integration could remove perverse incentives;
3. How different organisations could contribute to ensuring greater integration of care;
4. How preventative activities are deployed in relation to specialised care;
5. How the provision of earlier treatment locally is balanced against the need for specialised care;
6. How networked care can facilitate greater integration;
7. How effective shared care agreements and care planning are in the case of specialised services.

Overview of responses

Respondents agreed with the topics set out in the briefing materials, while also providing a number of other issues for consideration.

Many responses underlined the need for seamless care for patients, regardless of where in the system it is commissioned. In line with many other written responses, the Royal College of Surgeons noted that integration should be at “the heart” of the strategy. They felt that “there should be no impact on the way patients and the public experience care between specialised and non-specialised services” and that “national and local commissioners need to work together, along with patients and clinicians, when measuring the quality of care, as it may be that patient experience and outcome measures will cut across non-specialised and specialised services”.

Linked to this sentiment, specialist providers called for a tailored approach that supports the provision of specialist assessment and care in a way that fits the needs of the patient. This

could be consultations nearer the home, care delivered in a local hospital where possible but in a specialist centre when necessary.

Effective care plans were seen as an important way to deliver more integrated care for patients and it was felt that the strategy might usefully include measures to ensure use of care plans for patients using specialised services.

Participants at the event underlined the importance of involving local authorities in the development of specialised services. This was particularly relevant for services such as HIV which span across NHS England, CCG and local authority responsibility. Councillor Lisa Mulherin reiterated the importance of engagement with local authorities in her written submission. The integration pioneers were a positive development and she hoped that they would help tackle the siloed approach to working that precluded the integration of services.

Another key issue was the definition of commissioning responsibilities and attendees agreed that confusion regarding these responsibilities was a major obstacle to the integration of services.

> *"The focus to pool commissioning expertise at a national level to realise economies of scale and reduce regional variation should not be lost. Greater clarity over which parts of the patient pathway would be funded by CCGs vs NHS England would help here."* ***Medtronic***

Shared commissioning of services was advocated by a number of respondents as a means of addressing poorly coordinated transitions in the care pathway.

> *"It is clearly important that there is, at the very least, an alignment of commissioners across a service pathway. This could be developed further through co-commissioning (or collaborative commissioning) by which individual commissioners retain their own responsibilities but work collaboratively together to commission their elements of a pathway in a more coordinated manner."*
> ***Association of the British Pharmaceutical Industry (ABPI)***

Generally speaking, it was felt that current mechanisms for communication were insufficient and resulted in siloed working by the different elements of the services. Regular communication between CCGs, NHS England, HWBs and others was seen as crucial by attendees and respondents. One participant advised NHS England to 'speak CCGs' language'. The British HIV Association felt that "a regular, public coming together of leaders of NHS-E, PHE, local government and the Department of Health would be a simple first step in demonstrating commitment to joined-up working and commissioning".

Respondents noted that prevention activities would differ significantly in the case of specialised services, than for other areas of the NHS and suggested that the strategy might usefully include some clarity on the form that these activities might take. For example, written responses highlighted the importance of early diagnosis in achieving more integrated care:

> *"We would welcome an emphasis on earlier diagnosis of disease in the strategy, which could lead to substantial cost savings in terms of the demand for specialised services (less complex treatment, shorter hospital stays, lower maintenance etc.)"*
> ***Target Ovarian Cancer***

Integration was felt to be closely linked to accountability and attendees felt that clearer accountability mechanisms would help promote greater integration of services. Linked to this, perverse incentives also play a role in preventing integration and attendees suggested that the strategy might usefully chart a course to address these systemic issues. Equally, existing incentives might also be deployed more effectively with a view to encouraging good practice in relation to integration. Other considerations raised included the need for integrated data streams to support integration

> *"Tariff has not historically incentivised commissioners and providers to look at solutions that will help deliver value where primary care meets secondary care and where there is an impact on social care. There needs to be the further development of 'years of care' payments for patients with life-long conditions and a range of long-term chronic conditions. This should lead to the development of a system where NHS England commissions patient centred solutions and outcomes rather than just provider activity and hospital admission."* ***Medtronic***

Many respondents emphasised the importance of working in networks. This was seen as an important way to ensure that patients are cared for closer to home, while still ensuring that appropriate expertise is accessed when necessary. In addition, respondents highlighted the importance of making use of existing networks, including Strategic Clinical Networks and Operational Delivery Networks.

> *"Where appropriate, services should be delivered through a networked care approach which enables patients to benefit from specialist expertise whilst receiving treatment as close to home as possible, particularly where there are a small number of specialised centres for a service."* ***Asthma UK***

> *"An integrated system requires all stakeholders to work together to achieve the best outcomes for the communities and patients they serve. Networks resourced to enhance the patient pathway, to improve the collaboration across the pathway and to stimulate innovation to improve pathway problems and patient outcomes must be a core feature of the next strategy."* ***UCLPartners, London Cancer***

Integration between paediatric and adult specialised services was also seen as a crucial element of the strategy. Great Ormond Street Hospital noted that specialist paediatric services needed "to be appropriately linked through transitioning processes to equivalent specialist adult services".

The Royal College of Nursing's written response emphasised the importance of acknowledging the cost considerations related to integration, which might be substantial upfront where new services are developed but may pay dividends at a later date or a different point in the care pathway.

QUALITY AND SAFETY

Scoping recommendations:

- The strategy should provide clarity on how quality should be defined and measured
- The strategy should articulate how outcome measures can be used in assessing quality and should include clear commitments to ensure that they are used more widely
- The strategy should assess the merits of producing a best practice framework on data collection, registration and utilisation
- The strategy should set out recommendations for improving diagnosis and prevention
- The strategy should assess the benefits of national clinical databases (registries) and consider what information could be made publicly available
- The strategy should seek to describe clear guidance on quality and safety requirements for any potential reconfigurations within specialised services.

Overview

The initial briefing materials asked respondents whether the strategy should look at:

1. How quality is defined and measured;
2. How patient safety is accounted for and achieved in specialised services;
3. How quality and safety is defined in relation to potential reconfigurations;
4. How the availability of earlier diagnosis and screening for rarer conditions might be improved;
5. How the demand for national clinical databases might develop and whether information from these databases should be made available to the public in some form.

Overview of responses

Respondents reiterated the points made in the briefing as well as highlighting several other issues which warranted consideration.

A uniform definition of quality was seen as important by many respondents. This would help to ensure a consistent understanding of what quality should look like in specialised services for commissioners, providers, patients and external stakeholders.

> *"Under Quality and Safety we agree that a key part will be ensuring that quality is defined and measured. It will also be crucial for the strategy to consider the processes and principles for any resulting reconfigurations."* ***Communication Matters***

Outcomes data were identified as a key factor in assessing the quality of services. Attendees at the scoping event felt that the strategy should emphasise the importance of outcomes and should establish mechanisms for measuring the quality of services.

> *"In a climate where larger units with more access to supporting infrastructure appear to be favoured over smaller units, outcome data becomes key to ensuring the right providers are delivering the services."* ***Queen Victoria Hospital NHS***

Foundation Trust

It was suggested that the strategy might usefully address the collection of data on specialised services with a view to implementing a best practice framework. Several respondents highlighted the importance of developing metrics on patient quality and satisfaction and reflecting these in service specifications and commissioning policies. There were also calls for patient and public involvement in the establishment of these quality markers for specialised services.

"The strategy should commit to being clear on what quality means for each service and how it will be represented in metrics. The detail for each service will have to be described in the service specific strategy documents and service specifications." ***Roche Products***

Registries were also seen as useful mechanisms for ensuring national consistency and for collating relevant data.

"We suggest that robust registries are established and used to address atlas variations even if these are local registers of activity. One of the bodies must take on the responsibility to publish (yearly) the post code accessibility and nature of services provided." ***British Kidney Patient Association***

Attendees also felt that responsibility for quality and safety should be better defined between Monitor, CQC and specialised commissioners and suggested that the strategy might usefully set out these responsibilities. Some respondents set out that NHS England, as the commissioner of services, should take a more active role in driving quality and safety within services and supporting consistency across the country.

"In the current NHS system architecture it is easy to mistakenly place quality and safety solely at the door of organisations such as CQC and Monitor. However, the most immediate and powerful relationship in a system that creates separate providers and commissioners is the contractual one between those two parties. The strategy must make it explicit that NHS England will fully utilise all existing contract levers and when necessary work with stakeholders to create new contract levers to ensure quality and safety in service provision." ***Roche Products***

"NHS England need to work with more providers to develop CQINs linking to level of provision outlined in service specifications. These and similar initiatives would act as way to incentivise provision of and continued development of a quality service rather than simply one which meets any basic criteria." ***Muscular Dystrophy Campaign***

INNOVATION

Scoping recommendations:

- The strategy should include consideration of how NHS England encourages and manages innovation, including but not limited to products, technologies, service changes and clinical techniques
- The strategy should articulate a clear vision for how innovation is proactively encouraged by NHS England, tested and diffused through specialised commissioning. A clear vision for the processes for improving innovation in specialised services should be articulated
- The strategy should develop recommendations on how greater transparency will be provided on NHS England's processes and criteria for clinical prioritisation, including the assessment of innovation
- The strategy should provide clear commitments on how NHS England links with research for its specialised commissioning. This should include links with academic, clinical research and medical trials
- The strategy should define the future goals for NHS England's specialised commissioning links with other organisations relevant to innovation, such as NICE, the National Institute for Health Research, industry bodies and Academic Health Science Networks

Overview

The initial briefing materials asked respondents whether the strategy should look at:

1. How innovation is defined, eg products, services and clinical techniques
2. How well NHS England proactively seeks out innovation
3. How transparent NHS England's innovation processes are
4. How well aligned NHS England is with innovative research
5. How well NHS England links with NICE on the assessment and uptake of innovation
6. How savings arising from innovation are reinvested in specialised services

Overview of responses

Respondents strongly agreed with the topics set out in the briefing materials, while also providing a number of other issues for consideration.

Many respondents highlighted that innovation often originates in specialised services before being filtered throughout the wider NHS and felt that the strategy and NHS England's approach to innovation should reflect this. With this in mind, respondents suggested that the strategy should outline how innovation in specialised services will be supported and encouraged.

> *"Innovation should be the corner-stone of the five-year strategy for specialised services, clearly stated in the vision, in particular if patient outcomes in England are to match those achieved in other countries. Target Ovarian Cancer believes that it is vital that the strategy is explicit in its support of innovation as there appears currently to be some confusion within specialised commissioning on this point."* ***Target Ovarian Cancer***

Industry called for clarity on what evidence is required for new products and what value means. Generally speaking, it was felt that greater clarity and transparency was required around NHS England's processes for assessing and disseminating innovation.

> *"The strategy needs to pave the way for robust, transparent and timely processes for the evaluation and adoption of medicines unsuitable for assessment by NICE or pending such assessment."* ***Gilead***

Respondents also highlighted that NHS England should adopt a more long-term approach to innovation and suggested that the mechanisms for achieving this should be outlined in the strategy.

> *"NHS England must adopt a more systematic, long-term approach to funding innovation and the strategy should consider how this might be achieved. Horizon-scanning for novel technologies and procedures should become standard procedure, and the obstacles to this should be discussed in the strategy."* ***Federation of Specialist Hospitals***

> *"The strategy must plan for and fund changes in technology and innovation such as the expansion of genetics and all the new treatments that will flow from it."* ***Guy's and St Thomas' NHS Foundation Trust***

> *"Investment in technology to support the management of the patient across shared care arrangements and across the patient pathway from primary care through to secondary care and palliative care. This technology investment will be a key enabler for an integrated care system"* ***UCLPartners, London Cancer***

Links with academia were highlighted in a number of responses, with many urging NHS England to include some consideration of how these might be improved in the strategy. Respondents hoped that this would enable the NHS to become better aligned with advances occurring in academia and to ensure that patients were able to benefit from these advances as rapidly as possible.

> *"The specialised services strategy should link closely with the research strategy, as well as look to encourage more links with academia and industry, and really embed research as part of the day to day culture of delivering a specialised service."* ***Cancer Research UK***

> *"For innovation, we welcome reference to academic research to help inform the strategy and believe this would be strengthened by having research as one of the general principles running through the strategy. This would help to reflect the duty within the Health and Social Care Act 2012 for NHS England to promote research on matters relevant to the health service, and the use in the health service of evidence obtained from research."* ***British Heart Foundation***

> *"Macmillan supports the evaluation of how well aligned NHS England is with academic research on innovative products and techniques, as well as its integration with other research-led organisations internally and externally to the NHS, for example clinical trials."* ***Macmillan Cancer Support***

Similarly, it was felt that the role of the Academic Health Science Networks (AHSNs) should be clarified in the strategy. Respondents suggested that the AHSNs had an important role to play in improving the uptake of innovation but that further information was required before this opportunity could be captured fully.

> *"The strategy must consider mechanisms to promote innovation and spread of best practice in the NHS, such as the how Academic Health Science Networks will be utilised to help enhance the uptake of innovations".* ***Target Ovarian Cancer***

Responses also highlighted the need to improve uptake of medicines which were not being assessed by NICE. Similarly, the links between NHS England and NICE merit consideration in the strategy.

> *"We believe the strategy should consider […] how to drive access and uptake of those medicines being considered via CRGs rather than NICE appraisals in order that patients are not disadvantaged by unduly overlooked or delayed treatment."* ***GSK***

> *"Clarity is needed on the decision-making process for technologies/drugs which are not covered by NICE guidelines."* ***British Kidney Patient Association***

NICE supported the inclusion of an assessment of how NHS England links with NICE processes to support the roll out of innovation. They agreed that appropriate mechanisms, incorporating those systems that have already been established, should be set out in the strategy to support this.

> *"In the case of specialised services, the purpose of such links should be to ensure that: NHS England is fully aware of guidance relevant to specialised services in the NICE pipeline, and is able to contribute its expertise as commissioner of specialised services to the processes for choosing topics for NICE guidance development; NICE, through its Medical Technologies Evaluation Programme and Health Technology Adoption Programme, and by working with NHS England's Commissioning through Evaluation programme, supports NHS England in promoting innovation in specialised services."* ***NICE***

It was thought that the strategy should set out how NICE's Highly Specialised Technology evaluations would be incorporated into assessments from CRGs and ratified by the Rare Diseases Advisory Group (RDAG) and Clinical Priorities Advisory Group (CPAG).

> *"The strategy should also address the way in which the new Highly Specialised Technology Assessments that will be produced by the National Institute for Health and Care Excellence will be used together with the assessments made by the Clinical Reference Groups (CRGs) and ratified by the Rare Diseases Advisory Group (RDAG) and the Clinical Priorities Advisory Group (CPAG)."* ***Shire***

A number of responses from industry called for a specific section within the strategy that would focus on ensuring access to medicines, particularly given the recent suspension of the Specialised Services Commissioning Innovation Fund (SSCIF).

> *"The vision should consider the need to make sure the strategy has effective provisions for the uptake of innovation as highlighted in James Palmer's letter regarding cancellation of the Specialised Services Innovation fund (SSCIF) and NHS England's commitment to reinstating the fund within the future years or better still within the context of the 5 year strategy."* ***MSD***

It was also suggested that the strategy could set out plans to assess the performance in England against comparable countries in Europe, particularly in the area of access to new treatments. This would allow an assessment of the uptake of innovation through the new system.

> *"International benchmarking is an important tool in understanding performance in the UK versus the Rest of the World. The strategy should seek to go beyond bench marking alone and fully commit to learning how those countries with better outcomes attain them. The strategy should call on stakeholders to be a part of sharing this knowledge with and within NHS England."* ***Roche Products***

ANNEX A

Briefing for written submissions

SPECIALISED SERVICES FIVE YEAR STRATEGY
BRIEFING FOR WRITTEN SUBMISSIONS

This briefing is intended to support individuals and organisations to make a written submission to the specialised services strategy scoping process. Written submissions should be sent to dorothy.chen@shca.info by no later than Friday 13th December 2013.

Challenges and opportunities for specialised services

The five-year strategy for specialised services is being developed following a period of significant change in the structures of specialised commissioning. Until 31st March 2013, specialised commissioning was fragmented across a range of NHS organisations, including regional Specialised Commissioning Groups, a National Specialised Commissioning Team and all local Primary Care Trusts, which remained ultimately responsible for the specialised healthcare of their populations. From 1st April 2013, under the terms of the Health and Social Care Act 2012, NHS England became the sole direct commissioner of specialised services.

With a consolidated budget of approximately £11.8billion, NHS England is in a strong position to set a course for the future of specialised services. Within the overarching Call to Action, which opened a public debate about the future shape of the NHS, the five-year strategy for specialised services provides a vital opportunity to engage with patients, the public, NHS organisations and others, to articulate a clear vision for the future.

In doing so, the achievements of the past and the challenges of the future must be recognised. Assessing these in 2006, the Carter Report provided a series of recommendations for the future development of specialised services which served to guide many of the changes of the last seven years. The Carter Report recommended the pooling of budgets for specialised commissioning in Specialised Commissioning Groups, designation of specialised service providers, closer involvement of patients and the public in specialised commissioning and more robust governance across the board.

These and many other recommendations of the Carter Report have been met or exceeded in the seven years since its publication. As the sole commissioner of specialised services, NHS England has pooled resources at a national level, aligning these with commissioning expertise. Specialised service specifications and clinical commissioning policies are developed by multi-disciplinary Clinical Reference Groups and consulted upon publicly before coming into force. Across England, under a single commissioner, consistency in service standards is being brought about, with uniform access across the country and an end to the previous ‘postcode lottery’ under different local or regional commissioning bodies.

Yet significant challenges remain for the future direction of specialised services, as well as for many of the other recommendations made in the Carter Report. Carter recommended greater integration of care, so that specialised and non-specialised care could be provided seamlessly to patients; he urged closer alignment between the commissioning and payment systems to ensure incentives to providers pulled in the same direction; he recommended stronger commissioner accountability and clearer service-level costing information. On these fronts,

more progress needs to be made.

Furthermore, such challenges must now be met in a more difficult financial environment. The likelihood of flat funding for the health service in the next five years, set against increasing demand and cost inflation means that specialised services need to be transformed to deliver the greatest quality, value and outcomes possible. The five-year strategy for specialised services provides the opportunity to articulate this vision, refreshing Carter's priorities and developing new recommendations to ensure that future development of specialised services is undertaken strategically and focused on the needs of patients.

Scoping the five-year strategy for specialised services

A draft mission and vision for the future of specialised services will be put to a 12 week public consultation during spring 2014. In order to meet this timeframe, the scope of the overall strategy will need to be determined by the end of December 2013. To this end, an event is being held in London to bring together different stakeholders to discuss the strategy's scope, and written submissions are being invited from all individuals and organisations with an interest in the strategy.

Submissions may cover any themes or topics for inclusion within the scope, but should not relate to individual specialised services or groups of services, eg 'a strategy for cancer services'. Service-specific engagement will be carried out separately to develop priorities for individual services, alongside the overarching strategy. Overarching issues relating to condition areas, such as the need to make sure the strategy has effective provisions for highly specialised services or specialised mental health services, would fall within the scoping exercise, while specific recommendations for particular types of highly specialised or mental health service would not.

The publication of the UK Strategy for Rare Diseases will also contribute to the contents of the strategy. The UK Strategy for Rare Diseases encompasses a wide range of conditions, including but not limited to those covered by highly specialised services, and the recommendations of the UK Strategy that relate to NHS England's responsibilities for specialised commissioning will automatically form part of the scope of the five-year strategy for specialised services.

This briefing sets out our initial thinking on five suggested themes which could inform the scope of the strategy, recognising that some of the issues overlap. We would welcome comments on the merits or otherwise of these themes, and on any matter not covered which might usefully form part of the strategy.

THEMES FOR THE SPECIALISED SERVICES FIVE-YEAR STRATEGY

General principles

A number of core principles would cut across the themes of the strategy. For example, a commitment to including patients and the public in every stage of specialised commissioning, from policy development through to implementation and monitoring. The strategy might assess how the experiences of patients using specialised services can contribute to defining good outcomes, or how individual patients' views are captured and reflected in policy development.

Further, efficiency and value will need to run through all specialised commissioning. The strategy might suggest how NHS England could use its position as sole direct commissioner of specialised health services to drive efficiencies from providers and suppliers, work with local commissioners and assure the public that specialised commissioning secures the highest outcomes for the resource allocated.

The strategy might also elaborate upon an ethical approach to decision-making in specialised services, setting core principles to be applied through prioritisation and service reconfigurations in future. This could form part of the vision of the future of specialised commissioning, with a clear description of best practice in developing services and driving change in the NHS.

Themes for inclusion in the strategy might include:

Accountability

The strategy might make an assessment on the quality or outcomes requirements used as the benchmark for holding NHS England to account.

Within this topic, the strategy might also evaluate the present extent of transparency across NHS England's specialised commissioning. This could look at flagship transparency projects being led by the Patients and Information directorate insofar as they relate to specialised services, as well as how transparent the routine business and decision-making process of NHS England is. In addition to an assessment and recommendations on transparency, the strategy might also judge how accessible the information produced by NHS England is, and make recommendations for key areas of improvement to boost public understanding and engagement with specialised services.

In examining accountability, the strategy might also assess where responsibility for different aspects of specialised commissioning lies, as well as how overall responsibility for service quality is taken. Where possible, the strategy might look at how responsibility could be shared with patients and the public, along with local organisations, alongside strong accountability mechanisms for responsible individuals and groups within NHS England itself.

Money

The strategy could look at how money flows through specialised services to identify problems, perverse incentives or confusion and to make clear recommendations for the future. These recommendations could focus on the need to ensure clear and rigorous definition of the scope of specialised services, with consistency across the Manual, service specifications and Information Rules. It might examine clinical coding and how well aligned coding is with the contractual requirements of commissioners, making an assessment on whether commissioners' intentions are being accurately translated into action by providers.

Another area in which consistency is important is in the payment system, most notably the national tariff. Any issues in this area would need to be co-ordinated with the joint work being undertaken on the payment system by NHS England and Monitor.

As part of this work, the strategy could consider how well specialised services are currently costed. It might look at where financial oversight and support is used within the commissioning system, and whether this should be extended, changed or peeled back. This might touch upon the use of analytics or registries and how and whether increased usage in future could support

more informed commissioning.

The strategy might seek to determine the root causes of main drivers of cost in specialised services, or to develop proposals for how NHS England could better take account of these. Understanding the cost drivers which lead to growth in spend will be crucial for five-year planning in specialised services and might usefully fall within the scope of the strategy, linked with provisions on more granular costing and better databases and analytics.

Integration

Ensuring that patients experience care seamlessly is a high priority for the health service. For specialised services, which are commissioned separately from other health services, this represents a particular challenge. The strategy could examine how well this is working in practice, as well as any measures that could be taken to improve integration across care pathways. It might consider the ways in which closer integration could remove perverse incentives from the treatment pathway and 'cost shunting' between CCGs and NHS England, as well as how different organisations could contribute to ensuring greater integration of care.

In particular, there could be an opportunity for the strategy to place an emphasis on measures to prevent the development of ill health or complications requiring specialised services. This could include recommendations on providing earlier treatment locally to prevent incurring greater costs in specialised care. Such savings in the specialised budget would then release greater resource for non-specialised care to continue prevention work. The strategy could develop recommendations on these fronts.

The strategy could also examine integration in the context of networked care, ensuring that delivery of care can be as close to a patient's home as possible, balanced against the need for specialist expertise. Shared care arrangements between providers might therefore fall within the scope of the strategy, as would integration between specialised care providers and other local care providers, including community care.

This work could touch upon care plans and care coordination as a means of ensuring greater integration of care from the patient's perspective. The strategy could make recommendations on the desirability and feasibility of introducing these across specialised services.

Quality and safety

The strategy could consider quality and safety in specialised services in a number of ways. An assessment of how quality is defined and measured could be included within the scope of the strategy, as well as an examination of how patient safety is accounted for and achieved within specialised services.

This work could have broader relevance within the strategy, with the potential to describe clear guidance on quality and safety requirements for any proposed service reconfigurations. It could also serve to help assess the existing quality of services and any potential reconfiguration requirements. As a result of the challenges arising from NHS England's delivery of national service specifications, the strategy might consider processes and principles for any resulting service reconfigurations.

A core part of the assessment of quality in specialised services might relate back to the level of integration of care, as well as to the availability and accuracy of early diagnosis or screening

for rarer conditions. The extent and future demand for national clinical databases might also be considered in this context, to demonstrate measurement and assessment of quality and safety throughout specialised services. The strategy might assess whether such information should or could be available to patients and the public in some form, to enable more informed decision-making and patient choice in specialised services.

Innovation

The strategy might encompass innovation issues on a number of fronts. It could look at how well NHS England scans the horizon for upcoming innovation, including new products, services and clinical techniques. This might include assessment of how proactively and comprehensively innovation is detected, as well as how well it is adopted and diffused through specialised services to patients who could benefit.

Within this work, the strategy might also provide a judgment on how transparent NHS England's processes for finding and approving innovation are, and what, if anything, could be done to improve them. The strategy might also take a view on how transparently NHS England sets its criteria for determining whether innovation is funded, and what steps might need to be taken in future on this score. This transparency assessment might also take a broader view of the processes for spotting and taking up innovation in specialised services.

A further aspect of innovation that the strategy could consider relates to research. An evaluation of how well aligned NHS England is with academic research on innovative products and techniques, as well as its integration with other research-led organisations internally and externally to the NHS. This might also look at NHS England's approach to clinical trials and the criteria it uses to assess the potential of innovations early in the pipeline. It could investigate how local innovation can be escalated and rolled out at national level and how well unmet need is identified and articulated to relevant stakeholders to guide future innovation. This might include assessment of how well NHS England links with NICE.

The strategy could also develop principles around the reinvestment of savings gained from innovation, or the assessment of how costs and savings are calculated over the longer term to inform commissioning decisions. It could develop proposals on how and where savings need to be generated, as well as expectations for how such savings are then reinvested.

ANNEX B

External attendees at scoping event

1	Achim Schwenk	North Middlesex University
2	Adrian Berry	South West Yorkshire Partnership
3	Alaster Rutherford	Independent prescribing pharmacist
4	Alison Taylor	Children's Liver Disease Foundation
5	Allison Streetly	Public Health England
6	Andrew Wilkinson	Specialised Healthcare Alliance
7	Andy Cole	BLISS
8	Angela Douglas	British Society for Genetic Medicine
9	Angela Francis	Guy's and St Thomas' NHS Foundation Trust
10	Barbara Gallagher	Cancer Commissioning Team North West and South London
11	Bernard Quinn	NHS Brent , Ealing , Harrow & Hillingdon CCG
12	Beverley Dawkins	Mencap
13	Brian Gunson	British Liver Trust
14	Catherine Harris	Communication Matters
15	Christine Allmark	-
16	Claire Newton	Great Ormond Street Hospital for Children NHS Foundation Trust
17	Clive Woodward	St Jude Medical
18	Daisy Ellis	Terrence Higgins Trust
19	Dan Burden	Spinal Injuries Association
20	Daniel Phillips	Welsh Health Specialised Services Committee
21	Diane Thomson	Pfizer
22	Dianne Addei	Consultant in Public Health Medicine
23	Don Redding	National Voices
24	Douglas Lewins	-
25	Ed Owen	Cystic Fibrosis Trust
26	Farhana Ali	NHS England
27	Fay Scullion	Macmillan Cancer Support
28	Felicity Taylor	NHS England
29	Fiona Loud	British Kidney Patient Association
30	Genevieve Smyth	College of Occupational Therapists
31	Geoff Bellingan	University College London Hospitals NHS Foundation Trust
32	Gillian Adams	-
33	Hameed Khan	-
34	Hannah Connell	Royal National Hospital for Rheumatic Diseases NHS Foundation Trust
35	Hayley Sewell	Royal National Hospital for Rheumatic Diseases NHS Foundation Trust
36	Hilary Kelly	Wessex Strategy Clinical Network
37	Isabel Hemmings	Sheffield Children's Hospital NHS Foundation Trust
38	James Palmer	NHS England
39	Jane Anderson	Homerton University Hospital NHS Foundation Trust
40	Jane Deller	UK Genetic Testing Network

41	Janet Wild	Baxter
42	Jill Clayton-Smith	UK Clinical Genetics Society
43	Joanne Kennedy	Bradford Teaching Hospitals NHS Foundation Trust
44	John James	Sickle Cell Society
45	John Kell	Motor Neurone Disease Association
46	John Murray	Specialised Healthcare Alliance
47	John Reeves	-
48	Jonathan Howell	Public Health England
49	Joseph Tomlinson	GSK
50	Joshua Bridgens	Leeds Teaching Hospitals NHS Foundation Trust
51	Josie Godfrey	NICE
52	Judith Bell	Public Health England
53	Judith Connolly	Evelina London Children's Hospital
54	Kate Shields	Leicester University Hospitals NHS Foundation Trust
55	Katie Begg	Anthony Nolan
56	Keith A Godfrey	Gateshead Health
57	Kevin May	-
58	Kim Fleming	Royal Free London NHS Foundation Trust
59	Liane Langdon	NHS Leeds North CCG
60	Lisa Brereton	-
61	Lucy Davies	Royal Brompton & Harefield NHS Foundation Trust
62	Mandy Cripps	Salisbury NHS Foundation Trust
63	Mark Almond	Nova Healthcare
64	Mark Davis	Gilead
65	Mark Scott	Roche Products
66	Martha Burgess	Sanofi
67	Maxwell V Madzikanga	Independent
68	Melanie Hiorns	Great Ormond Street Hospital for Children NHS Foundation Trust
69	Melanie Sturtevant	Asthma UK
70	Melinda Bertwistle	AbbVie Ltd
71	Mike Foster	University College London Hospitals NHS Foundation Trust
72	Mike Ringe	ABPI
73	Mirella Marlow	NICE
74	Nicholas Palmer	National Kidney Federation
75	Nick Meade	Genetic Alliance UK
76	Nicki James	-
77	Nishan Sunthares	ABHI
78	Nourieh Hoveyda	NHS consultant in public health medicine
79	Oliver Bloor	Milton Keynes Hospital NHS Foundation Trust
80	Patrick Leahy	Royal College of Surgeons
81	Paul Fenlon	Department of Health
82	Paul Hodge	Abbott
83	Peter Davies	Epsom & St Helier University Hospitals NHS Trust
84	Ray Storey	-
85	Rebecca Johnson	Muscular Dystrophy Campaign
86	Richard Jarvis	Novartis

87	Robert Courteney-Harris	University Hospital of North Staffordshire NHS Trust
88	Rosanna Preston	CLAPA
89	Ruth Bridgeman	NHS Improving Quality
90	Sally Percy	The Neurological Alliance
91	Samantha Milbank	Interim QIPP Programme Director
92	Sarah Kramer	Royal College of Speech and Language Therapists
93	Sasha Daly	Teenage Cancer Trust
94	Sasha Singh	City and Hackney Centre for Mental Health
95	Shah Kamaly	BT
96	Simon Dent	-
97	Stephen Bridge	Papworth Hospital NHS Foundation Trust
98	Sue Kilby	Janssen-Cilag
99	Sue Millman	Ataxia UK/PPE Steering Group
100	Temitope Bolaji-Jegede	NHS Central Southern CSU
101	Tom Smith	British Society of Gastroenterology
102	Tony Griffiths	St Andrew's - Northampton
103	Vin Diwakar	Birmingham Children's Hospital NHS Foundation Trust
104	Vincent Chippriott	-
105	Will Cleary-Gray	NHS Sheffield CCG
106	Zoë Molyneux	Cancer Research UK

ANNEX C

Written respondents to the scoping document

1	AbbVie
2	Actelion
3	Alder Hey Children's Hospital
4	Association of the British Pharmaceutical Industry (ABPI)
5	Asthma UK
6	Baxter
7	Birmingham Children's Hospital NHS Foundation Trust
8	Boston Scientific
9	British Gynaecological Cancer Society Commissioning Sub-Group
10	British Heart Foundation
11	British HIV Association
12	British Kidney Patient Association
13	Cancer Research UK
14	City Hospitals Sunderland NHS Foundation Trust
15	Communication Matters
16	Councillor John Illingworth (Leeds City Council)
18	Councillor Lisa Mulherin (Leeds City Council)
19	David Reid (patient)
20	Dudley Group of Hospitals
21	ENT UK
22	European Medicines Group (EMG)
23	Federation of Specialist Hospitals
24	Freedom from Torture
25	Gilead
26	GlaxoSmithKline (GSK)
27	Great Ormond Street Hospital for Children NHS Foundation Trust
28	Guy's and St Thomas' NHS Foundation Trust
29	Johnson & Johnson
17	Macmillan Cancer Support
30	Mark Sopher, Chair, CRG for complex invasive cardiology
31	Medtronic
32	MSD
33	Muscular Dystrophy Campaign
34	National Cancer Research Institute clinical and translational radiotherapy research working group (CTRad)
35	NHS Confederation
36	NICE
37	North East London Sexual Health and HIV Clinical Network
38	Pelvic Pain Support Network
39	Pfizer
40	Queen Victoria Hospital NHS Foundation Trust
41	Roche Products
42	Royal College of Nursing

43	Royal College of Surgeons England
44	Royal National Hospital for Rheumatic Diseases NHS Foundation Trust
45	Sheffield Children's NHS Foundation Trust
46	Shire
47	South Essex Partnership Trust
48	Specialist Orthopaedic Alliance
49	Target Ovarian Cancer
52	Turning Point
50	UCLPartners, London Cancer
51	Vascular Society
51	ViroPharma

[1] http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/DH_4135174