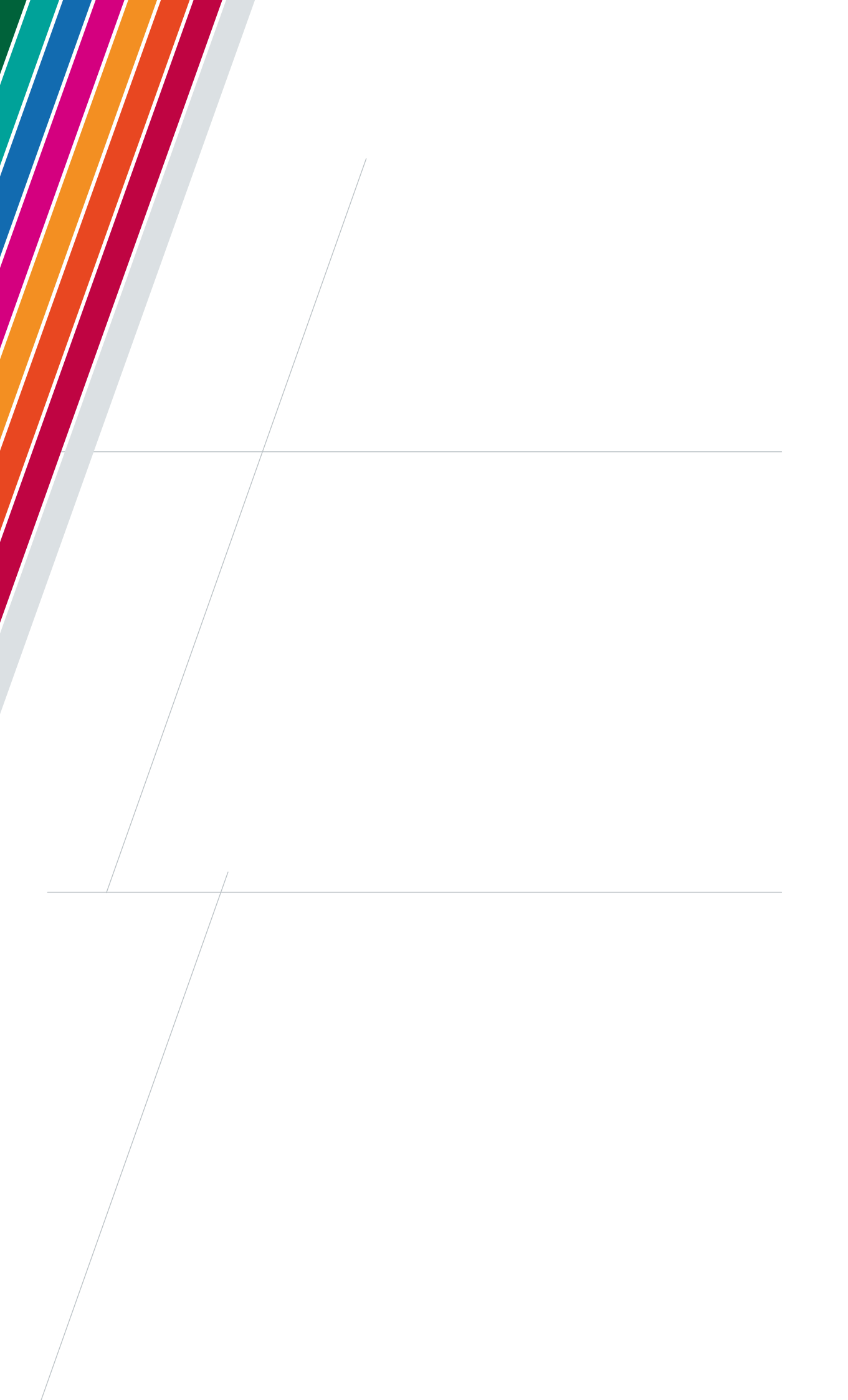




# SPECIALISED SERVICES: TRANSFORMING DELIVERY FOR PATIENTS

FEBRUARY 2020





Welcome to the fifth publication in our *Provider voices* series, in which we highlight the views of senior leaders on the key issues facing the NHS today.

We hope the series will make a valuable contribution to discussions on how health and care services can respond to challenges ahead and how the NHS can implement its new long term plan effectively.

Our topic in this publication is *Specialised services: transforming delivery for patients*. The NHS landscape is evolving quickly. Specialised services have a key role to play in helping to deliver the ambitions of the long term plan. They are well placed to lead the changes in patient care on many fronts, for example in supporting innovation, deploying new treatments and harnessing digital technology. Yet there are also particular challenges in adapting to new system structures and commissioning arrangements.

We have interviewed eight leaders who bring a range of perspectives on the challenges and opportunities facing specialised services. They include views from trusts operating in the acute and mental health sectors, a commissioner, a clinician and a leading charity speaking on behalf of patients. They all share a common goal, which is to deliver high-quality care for patients and service users.

We are grateful to the leaders who took the time to contribute to this publication and we would like to thank Helen Crump for carrying out the interviews.



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## SPECIALISED SERVICES: TRANSFORMING DELIVERY FOR PATIENTS

This year, the NHS is expected to spend around £20bn on specialised services commissioned by NHS England, which is around 17% of the total NHS budget. The term 'specialised services' covers a wide variety of treatments, from proton beam therapy to forensic mental health services for young people. These services deliver leading edge care to patients and service users often with rare or complex conditions. Each service is faced with a different set of challenges and operates in vastly different contexts, yet too often 'specialised' services are thought of as a homogenous sector that requires a one-size-fits all approach.

The way specialised care is commissioned and delivered also varies considerably depending on the nature of the service, the patient population and the facilities available within a particular geography – there are a small number of specialist providers in England, tertiary centres that deliver specialist activity alongside more common services, and mental health providers undertaking specialist mental health activity, often within a networked model with a lead provider and additional responsibilities delegated from NHS England. Many specialised services are world class, drawing patients from across the globe, some operate on a national patient population and some operate in regional hubs.

As colleagues in NHS England reflect on their overall approach to specialised services and the contribution they make to delivering the long term plan, it seems timely to inform that debate with a range of perspectives. This series of eight interviews with trust leaders, policy experts and other key stakeholders explores some of the challenges and opportunities for specialised services across the country. From commissioning approaches, to improving outcomes, to embracing innovation, all of our contributors reflected a strong desire to deliver excellent outcomes, support pioneering treatments and deliver improvements for patients.

### The relationship between specialised services and system working

For some time, the NHS policy landscape has been dominated by the drive towards system working, first with the introduction of sustainability and transformation partnerships (STPs) and then integrated care systems (ICSs). Health and care organisations recognise the need to work more closely within their local areas and systems bringing together primary, secondary and social care services, and working more closely with clinical commissioning group (CCG) colleagues. However, for providers of specialised services, the landscape is more complex. The nature of the activity and the geographic spread of the patient population, means national policy makers, trusts and their partners are having to think differently about how to make specialised services work within the STP/ICS framework.



Patients often travel long distances to access specialised care. As Matthew Shaw, chief executive of Great Ormond Street Hospital NHS Foundation Trust, points out, only 4% of the trust’s work actually originates from its local STP, but “now we’re having to think around how to retro-fit specialist services into a new world of local systems”.

John Murray, director of the federation of specialist hospitals, believes there is a balance to be struck: *“The NHS tends to be a victim of fashion. It goes from one extreme to the other – one minute it wants everything to be ultra-local, the next everybody wants to run the NHS by national diktat. If we’re honest with ourselves, it needs to be more nuanced, and I hope it will be. But there have been occasions over the last few years when there’s been this very definite view that we’ve got to move to local population planning, and we know from experience that with many of the specialised services that isn’t appropriate. So I would hope there can be a sensible discussion and balance struck.”*



***We need a much stronger collaborative network between providers of specialised services and commissioners of specialised services.***

Many define the success of system working on the basis of the maturity of local relationships, but as Mark Brandreth, chief executive of the Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust, suggests, specialised services can often feel “too distant” and “too remote” to properly take part in these conversations.

To be clear, these providers aren’t against the STP/ICS agenda, the point is that they are having to think differently about what this means for their services. Mark Brandreth believes there is still work to do: *“I’m a massive supporter of the ICS process. I think it’s completely the right thing to do, but if the paradigm we’re moving to is ‘competition is dead and it’s all about collaboration’, we need a much stronger collaborative network between providers of specialised services and commissioners of specialised services.”*

## Making commissioning work

Commissioning arrangements often form the focus of a conversation to bring specialised services into system working. In recent years, specialised commissioning arrangements have felt transactional to many providers, but in the context of system working, many see an opportunity to change the landscape in order to make it work better for patients and service users. There are many considerations here, such as appropriate commissioning footprints, payment reform and governance arrangements, with varying approaches emerging across the country. Our previous *Provider voices* publication, *Where next for commissioning?* discussed developments to move commissioning more broadly to a strategic function.



Naturally, the role of the STP/ICS itself in taking on responsibilities for specialised commissioning has been discussed. Paula Head, chief executive at University Hospitals Southampton Foundation Trust (UHS), however, opposes the move towards delegating commissioning to ICSs because of the uneven distribution of specialist centres: *"...delegating specialised commissioning to an ICS without a large specialist hospital will impact on those systems with a hospital like UHS within its catchment. The size of the system footprint won't be appropriate for certain services."*

In other parts of the country, ICS planning boards are being set up to give local systems a greater say in commissioning decisions made by NHS England. Louise Patten, chief executive at Oxfordshire and Buckinghamshire CCGs, is optimistic about commissioning end to end services for populations this way, but accepts services will still need to be commissioned at scale: *"The movement to try and get local CCGs involved in specialised commissioning is relatively immature but we have clear plans to set up our ICS specialised commissioning planning board. This isn't just about doing our bit of specialised commissioning for our population – specialised services have to be commissioned at scale. We don't want to lose the subject matter experts we currently have, but there is a need to develop the network of specialised commissioning. We should be further developing specialised commissioners to work alongside and in partnership with tertiary, secondary and primary care providers to really understand, technically and managerially, how best to commission that end to end service for populations."*



***This isn't just about doing our bit of specialised commissioning for our population – specialised services have to be commissioned at scale.***

For others, the new NHS England and Improvement regional structures are a more appropriate footprint to discuss specialised commissioning. Johanna Moss, director of strategy and business development at Moorfields Eye Hospital NHS Foundation Trust, believes a regional footprint gives her trust a greater voice across various STPs in which it delivers services: *"The creation of the NHS England and Improvement London region offers a real opportunity for a clear commissioning voice for the capital that supports greater efficiency and reduces waste and*

*duplication in the system... There is some great clinical collaboration at STP level, bringing together providers and commissioners: the added value the London region can bring for us is to provide a strategic framework for these collaborations and act as a real catalyst for widespread positive change."*

In specialised mental health services, the story is different again. Many mental health provider collaboratives have seen considerable improvements in both quality and efficiency by commissioning specialised mental health services under lead provider arrangements. Dr Jason Fee, clinical director for the South West Provider Collaborative,

is clear about the benefits this is bringing: *"One of the benefits of this programme is that we were able to harness senior clinical leadership, bringing senior clinicians on board at the very beginning. I think it's the coming together of these senior clinicians and the senior operational managers to co-design solutions that has been one of the key enablers of our success... This has turned commissioning on its head and put clinical drivers at the forefront of service re-design rather than financial or other aspects."*

## Improving the patient experience

System structures and commissioning arrangements are of course only a means to an end. The real prize is improving the care delivered to patients and service users. Once again, there are a number of specific considerations because of the nature of specialised services. Often specialised services are at the forefront of the latest clinical developments, treating patients with rare and complex conditions.

Gemma Peters, chief executive at Bloodwise, explains some of the frustrations of blood cancer patients: *"Because science in blood cancer is moving so quickly, the other challenge that we hear about a lot is that there's not one established treatment path... That can be overwhelming for cancer patients and they often feel that they have no agency in that decision-making process. Perhaps the most distressing point is end of life, where there seems to be a high occurrence of blood cancer patients not feeling like they were given all the information about the likelihood of treatments working."*

Louise Patten expresses her own concerns about the patient experience: *"The biggest frustration I experience are the letters of complaint, often from the patients themselves, who are trying to get hold of their next prescription or their next episode of local care. We don't link up pathways very well for the person, either with their local district hospital or into primary care."*

Similarly, Mark Brandreth thinks there is work to do to improve the link up with step down care once a patient has been discharged from a specialised service: *"There are issues about what happens beyond discharge. My consultants get very anxious about the follow-up care that the patients they're seeing will get once they are back in their communities. The consequence is that we hang onto patients longer than we should need to, and we also bring patients back to a specialist centre when they could be supported with appropriate follow on, or step down care locally."*

If these are some of the challenges, what are the solutions? Gemma Peters argues for a stronger patient voice in specialised services: *"We have some examples of patients treated at organisations where they feel they have been really involved in discussions about their treatment, and also in the wider decisions of trusts about how they provide services. We work*





*closely with NHS England to ensure that patients' voices are represented. There are some really good examples, but it isn't universal."*

Paula Head believes the key to unlocking better quality of care is staff engagement: *"I think that there is a direct correlation between staff involvement in the trust and the quality of outcomes for patients... We make sure the environment allows them to have freedom to innovate, an opportunity to work with inspirational people in an organisation that cares about people – both patients and staff."*

### Investing in capacity to meet demand

There remains an ongoing challenge to keep up with demand for services. Like the rest of the NHS, within a constrained financial envelope and amid workforce challenges, providers of specialised services are struggling to create additional capacity. In specialised services, this issue is magnified by the growth of personalised medicine, where rare conditions often require treatment which is customised for individual patients.

This can mean that there is variation in terms of patient access across the country, as Gemma Peters explains: *"There's huge variation in whether patients will be offered trials or offered the trials that are the most appropriate for their condition. That varies around the country and it's an area of real concern for us."* Matthew Shaw believes there are two stark choices: *"The honest conversation we need at a national level is whether we are willing to pay more taxes and spend a higher percentage of GDP on healthcare to fund these new treatments for an increasing population. Or if not, what services we have to withdraw from."*



***The honest conversation we need at a national level is whether we are willing to pay more taxes and spend a higher percentage of GDP on healthcare to fund these new treatments for an increasing population.***

For many trusts, it is the ongoing workforce crisis that means they are struggling to cope with demand. Mark Brandreth is concerned the ongoing pension issue is undermining the long term workforce strategy for specialised surgeons: *"About 30% of our work is done on an out-of-job plan basis above what's in our contracts of employment. The pensions issue has been totally devastating. Spinal surgeons are not ten-a-penny and to do the really complex work often involves two surgeons operating together over a ten-hour period. It's not something where you can suddenly increase capacity. These are senior experienced consultants that we need to look after, and get them to train and develop others through the ranks. It takes a good surgeon seven to ten years to get up to this standard – you can't fast track that. We've invested in some really good young spinal surgeons but I have to take a long-term view."*



However, all of the specialised service providers we spoke to were solutions-focused in their approach. In the south west, Dr Jason Fee believes increasing community capacity for forensic services is one way to support patients and service users more effectively and appropriately: *“One of our key strategic aims was to invest in community provision as an alternative to inpatient services, as we released efficiency savings by reducing the cost of the total inpatient cohort. A further benefit of community forensic services is that where they are co-located with an inpatient service, you divert service users at the very beginning because there’s a community alternative. You also reduce their length of stay if they do need admission because there’s a very clear care pathway set out from the beginning of the admission. This enables you to use your inpatient beds more efficiently, thereby enabling you to reduce practices of sending people out of area to access care.”*

Technology undoubtedly also has a role to play in tackling these challenges, as Matthew Shaw explains: *“What we’re seeing is an ever-expanding ability to treat people effectively via new technologies, but some of those technologies are phenomenally expensive. If you look at CAR-T cells [genetically engineered T cells for use in immunotherapy], patients who would have had very high mortalities from recurrent cancers are now potentially curable with very expensive technologies where we alter and use cells to attack cancer within the body. We are only treating a few patients at the moment but the inclusion criteria will likely expand over time and it’s a technology we think we can use in different areas.”*



***Specialised services are a national asset that we should invest in in order to continue delivering world class and innovative services.***

### Research, innovation and technology

The opportunities to improve specialised provision with technological advancements are extensive. Delivering specialised services often requires strong operational and clinical links into research, innovation and technology communities. The work done at the

front line of specialised service provision can be ground breaking and world class. It is an area that excites many and contributes to the NHS brand globally.

Johanna Moss is one of those excited by digital innovation work done at Moorfields and the opportunities this will present: *“We’ve recently been awarded a Health Data Research UK bid, which is being led by the University of Birmingham, with partners including Google Deep Mind, patient organisations and other commercial organisations. It’s a great example of where access to new funding sources are creating opportunities for us to explore and realise the potential of digital.”*

John Murray thinks there is a national opportunity to leverage innovation within specialised services: *"We actually have national assets here in terms of healthcare delivery, but also in terms of the economic potential of the NHS. One of the really exciting things with the long term plan is to discuss how you can leverage the expertise of these national centres of excellence to diffuse innovation throughout the wider NHS. For that to happen, these centres need to be integrated with the wider NHS in a way which perhaps hasn't always happened in the past."*

But our participants are clear these opportunities depend on access to sufficient capital funding to invest in new technologies and innovations. Matthew Shaw wants a more honest conversation about how much it costs to invest in digital technologies: *"[providers must not] fall at the first hurdle by failing to invest in the changes required"*.

## Where next for specialised services?

Change is afoot across specialised services. In the world of system working, providers and commissioners are thinking differently about how they integrate specialised services into whole population pathways. These changes are happening organically based on the different relationships and services being considered. There will always remain a strong national component to specialised commissioning, particularly in the development of service specifications. And our contributors did not see any excuse for variation of outcomes or access across the country – indeed they saw it as a challenge to be overcome.

What's clear from these interviews is that there is a clear opportunity and desire to drive innovation and transform delivery. Specialised services are a national asset that we should invest in in order to continue delivering world class and innovative services. They provide fantastic opportunities for talented NHS staff to develop world renowned skills and break new ground in medical research. They offer a lifeline and irreplaceable support for individuals in need of treatment and care which they cannot access outside of the NHS. As Gemma Peters' puts it: *"99% of patients would have no language to describe specialised care – it's just their health and their health care. [Although] the complexity of the system doesn't help patients to have agency... The ongoing commitment to new and innovative treatment is really exciting and positive: and... being able to provide [specialised services] is an important part of the NHS remaining loved and respected by the public."*

### **Miriam Deakin**

Director of Policy and Strategy, NHS Providers

With thanks to Helen Crump, Director, Cogency Analysis & Research for additional research and input



# THE INTERVIEWS



## MARK BRANDRETH

Chief Executive  
THE ROBERT JONES AND AGNES HUNT ORTHOPAEDIC HOSPITAL  
NHS FOUNDATION TRUST



Mark has been the chief executive at Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust since April 2016. He joined from the Countess of Chester NHS Foundation Trust where he was deputy chief executive and director of operations and planning. Mark has also worked in Wales and was invited to work for a period in a national role at the Department of Health. He has a particular interest in improving services for patients and improving organisational culture and change.

Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust is a specialist orthopaedic hospital. We carry out more hip and knee replacements than any other hospital in England. We also are one of the biggest centres for hip and knee revisions for patients that are having a second replacement because of infection, or for other reasons. We manage the spinal cord injury unit for the whole region, are one of the national bone cancer units and provide specialist paediatric orthopaedic care.

There are currently some significant issues with the commissioning of specialised services nationally. It's an area where we have all faced challenges in getting the right approach. I appreciate a lot of thinking is underway at NHS England and with colleagues across the sector now to make improvements and there are some changes coming.

There's been a lot of short-termism in the approach in recent times – a lot of these services are propped up on out-of-job plan working because the demand and capacity available don't match, and there's a lack of realistic long-term planning. For instance, we are about 50 spinal cord injury beds missing in the country. Demand is going up and up and we're nine beds short for our region. These are real and serious issues affecting patients, staff and trust viability.

However, now providers are taking on the challenge themselves and working together. The chief executives of all the spinal cord injury centres across the country recently got together to explore what we think the issues facing the service are and what we can do together. I see that as a real positive and a chance to bring together those with the most expertise and insight into these specialised services to see what we can do to forge a more effective delivery model.

### Integrated care systems

In the development of ICSs, the role of services bigger than the population served by the ICS has not been thought about well. Trying to work out how those services get a voice and get considered is an issue.

An ICS is a series of more mature relationships, where issues and risks are being shared across the system. Most district general hospitals have moved off payment by results, and are moving on to versions of risk sharing contracts – block contracts, but where some of the risk is covered.

Locally, we've got a risk-share contract for musculoskeletal conditions with our commissioners. It's not perfect, but it gives you a sense of the direction we're moving in. It's in our interest and theirs to have an economically viable system that can meet demand – so it's in both our interests to prevent people getting bad hips, knees and backs, rather than just looking after them when they're sick. We're part of that locally, but



that hasn't happened in specialised services because there's not the same level of maturity, trust or relationship in the system. It's too distant, it's too remote.

I'm a massive supporter of the ICS process. I think it's completely the right thing to do, but if the paradigm we're moving to is 'competition is dead and it's all about collaboration', we need a much stronger collaborative network between providers of specialised services and commissioners of specialised services.

### Maintaining and improving care quality

From a surgical point of view, the outcome and experience data all show that you want to be operated on by a surgeon that's done 50 of those this year, not two. The outcomes and the value for those patients is way better when there's a combination of a surgeon doing enough procedures and the centre doing enough. We know district general hospitals (DGHs) have to concentrate more and more on the frail elderly. As their skill base changes, it's very difficult to do anything that is low volume/high acuity orthopaedic surgery in a DGH because they're not doing enough of it. In a way this should force more reconfiguration and more surgical networks, but we all know how much that's been resisted.

As a sector, the specialist trusts have got the patient experience right through the staff experience. That's because the organisations tend to be smaller and focused. From a patient's point of view, they are experiencing world-class care, usually consultant-delivered. There are issues about what happens beyond discharge. My consultants get very anxious about the follow-up care that the patients they're seeing will get once they are back in their communities. The consequence is that we hang onto patients longer than we should need to, and we also bring patients back to a specialist centre when they could be supported with appropriate follow on, or step down care locally.



*I'm a massive supporter of the ICS process. I think it's completely the right thing to do.*

The way we are responding to the drive to provide more care in community settings is working in partnership, we are leading the development of new musculoskeletal pathways across the whole county. It doesn't mean every physio and occupational therapist will work for us, but what it means is that we'll ensure a gold standard quality of services right across the piece and we'll do that with our colleagues in the community hospitals and local authorities. That's our contribution to the system work – to take what we're good at and try to enshrine it across all the providers.

We also provide the orthopaedic trauma service at the local DGH. We support our partners – we're very much part of the system. We are a small hospital so we're dependent on our neighbours for a range of medical



services to support our infrastructure too – our biomedical science service and our blood service and so on is provided by the hospital down the road. Anyone running effective healthcare now cannot possibly be an island – it’s impossible to do it.

### Capital and workforce challenges

Access to capital is a problem and we are less efficient because of a lack of access to that funding. Do we need a national approach to capital? Yes, definitely. We opened a new £10m theatre three years ago and it was completely vital to our continued success. We now don’t have the prospect of doing anything like that again.

If in two years’ time I could get access to £20m capital, I could save £10m per year recurrently through efficiency and increased work. We’ve got outdated kit – we need a new EPR [electronic patient record] for example. We also need to make updates to physical buildings, and to diagnostics kit – the kit is getting more expensive because it’s better quality, and the quality of the images makes us safer. The element that is really worrying me is investment. That’s where I think we’re particularly starved at the moment.

About 30% of our work is done on an out-of-job plan basis, above what’s in our contracts of employment. The pensions issue has been totally devastating – spinal surgeons are not ten-a-penny and to do the really complex work often involves two surgeons operating together over a ten-hour period. It’s not something where you can suddenly increase capacity.

These are senior experienced consultants that we need to look after, and get them to train and develop others through the ranks. It takes a good surgeon seven to ten years to get up to this standard – you can’t fast track that. We’ve invested in some really good young spinal surgeons but I have to take a long-term view. As a specialist centre, we are an attractive employer so I am still able to recruit. I don’t have a big problem recruiting doctors but the trust struggles to attract and retain scrub and ward nurses, although if you look at us compared with many places I realise as a specialist trust, on balance, we have many strengths. I hope that the staff experience we offer means that we can become fully established for nurses in the next period. That would be a real achievement and something we intend to deliver.



***That’s our contribution to the system work – to take what we’re good at and try to enshrine it across all the providers.***



## JASON FEE

Clinical Director SOUTH WEST PROVIDER COLLABORATIVE  
Consultant Forensic Psychiatrist DEVON PARTNERSHIP NHS TRUST



Jason is the clinical director for South West Provider Collaborative for Devon Partnership NHS Trust and is responsible for directing the re-design of clinical care pathways across the south west, in order to ensure that individuals in receipt of secure care are treated as close to home as possible, for the shortest possible period, within the least restrictive level. Jason is an experienced consultant forensic psychiatrist and previous clinical director of a good/outstanding rated secure service. He has worked within healthcare settings both internationally and within the NHS over the course of his career.

Mental health services for adults in low and medium secure care are commissioned by NHS England. Following a number of reviews, it was quite clear that there was an escalating demand for secure services as well as escalating costs, but there was no clear agreed clinical model or other mitigations to address these escalations, other than a moratorium on further procurement of secure services.

Incremental contracting over several years had left services uncoordinated. Clinicians and managers of services were trying to do the best for their populations, but by working in isolation the population need of the entire region was poorly understood. A number of reports essentially recommended placing providers and senior clinicians at the heart commissioning for their populations. A number of national pilots, aligned to the aims articulated in *The five year forward view*, were launched across the country. Known as the new care

models, these pilots would bring together providers, senior clinicians and service users to co-design services to meet the needs of the population.

We were one of four sites chosen to become a secure services new care model. In 2016-17 the budget spend on secure care inpatient services was transferred to South West Provider Collaborative, allowing us to redesign services within the cash envelope. The aim was to ensure that anybody who needs to receive adult medium and low secure care gets it as close to home as possible, at the right level of security and for the shortest possible period. A further aim was to develop viable community alternatives to inpatient care (where appropriate) considering this first and foremost, rather than just admitting the person to inpatient services.

Our partnership is made up of five NHS organisations, one community interest company and two independent sector providers. One area where we are different from the other new care models is that every provider that provides medium and low secure services in the south west is part of our partnership. When we went live, we spanned 11 CCGs, covering a 22,000 square kilometre footprint and serving a population of five million.

### Caring for patients closer to home

We had to either find a way of providing a community alternative or increase capacity in region by building more hospital beds to bring people closer to home. Historically, the south west has been under-provided for. There were more than 400 people in adult low and medium secure inpatient beds when we went live and more than 200 of them were being treated outside the south west. We had under provision of female services in particular – when we went live nearly 80% of our female patients needing secure services were dotted around the country compared to almost 50% of our males.





All our in-region providers worked in separate silos, so there was no overview of the total bed stock. If somebody from Cornwall needed a male low secure bed but the low secure service in Cornwall was full, the system would place the person wherever the first available bed in the country was identified. That might have been in Norwich – there was no consideration of whether there might have been a bed available just over the border in Devon.

Only two of the now six STP footprints – Cornwall and Somerset – had a community forensic team, so for all the other areas, the only way to access specialist forensic services was by being admitted as an inpatient. One of our key strategic aims was to invest in community provision as an alternative to inpatient services, as we released efficiency savings by reducing the cost of the total inpatient cohort.

A further benefit of community forensic services is that where they are co-located with an inpatient service, you divert service users at the very beginning because there’s a community alternative. You also reduce their length of stay if they do need admission because there’s a very clear care pathway set out from the beginning of the admission. This enables you to use your inpatient beds more efficiently, thereby enabling you to reduce practices of sending people out of area to access care.

### Making change in the absence of pump-priming funds

One of the asks at the beginning of this programme was for pump-priming investment in order to fund community forensic teams as we saw these as the vehicle for achieving the change needed. Unfortunately this was not available, but as the national programme progressed, money was eventually released and this was re-invested in national pilots for specialist community forensic teams. We were fortunate to succeed in our bid to be a wave 1 pilot site in Devon. In March 2020 it will have been in operation for two years.

That team has already demonstrated efficiency savings by reducing the number of people in secure services for the population they serve (namely Devon). As they’ve reduced the number of people, we’ve been able to use fewer and fewer out-of-area beds. This, alongside other initiatives, has reduced the number of people in secure inpatient services within region, as well as reduced the length of time they stay in these services, to the point where our efficiency savings release is more than enough to fully fund this service from April 2020.

We have now also secured funding for wave two specialist community forensic teams in one of our other big



***We had to either find a way of providing a community alternative or increase capacity in region by building more hospital beds to bring people closer to home.***

providers. We are more than hopeful that the gains made for Devon can now expand into Bristol, North Somerset and South Gloucester.

We've also been able to support investment in specialist personality disorder community forensic services, which has potential in releasing further efficiencies that we can then use to invest in community services, ensuring the entire south west benefits from comprehensive specialist community forensic team coverage. In hindsight, if there was pump-priming earlier in this whole programme, I think we'd probably have been a lot further along than we are now.

The other bit that we can celebrate is that, at absolutely no cost to the health economy, we've commissioned a new 75 bedded secure service in our region. One of our providers, Elysium, is providing this hospital right in the centre of our geography. Elysium provided the capital and built the facility. We filled this facility with people from the south west who needed secure inpatient care but were placed miles from home in out of region beds. So instead of paying for them to be treated miles from home, we pay for them to be treated in region. Only people from the south west use those beds. They have come home to the south west.

According to our latest figures, we've now repatriated over 140 people. Where we started with over 200 people out of region, we've now got less than 40 people left out of region to repatriate home. All of this has been delivered without any additional cost.

We do have a gain and risk share arrangement with some of our partners. Over the first two years we continued to see the escalation in demand and costs leading to cost pressures of £16m, however, these were offset by £15m worth of clinical efficiencies. Between the risk and gain share providers, we incurred a cost of about £1m over the first two years. But this year all our innovations and initiatives are starting to bear dividends so we've now been able to pay that back as well as invest and have a sustainable business model. It hasn't come without having a high-risk appetite.

## Creating stronger bonds between specialist and generalist services

Historically, NHS specialised commissioning was very niche, and many local commissioners saw it as something that NHS England did that they don't need to get involved in. The devolvement back into provider collaboratives has reignited the sense of responsibility within the south west.

As lead provider, employed by Devon Partnership NHS Trust, we have fully divested ourselves from the provider arm in terms of governance and leadership. Our governance has an internal firewall all the way to board level. We quality assure and performance manage Devon



Partnership Trust's provider arm in the same way as we would any other organisation. We do work closely with our CCG colleagues quality assuring the services we commission and we've designed our governance from scratch, which I think is a good thing as it truly forces innovative solutions.

We have also had to work closely with CCGs through the STP's developing joint commissioning intentions, as we've now moved into commissioning community forensic services, which traditionally CCGs have commissioned. We want to ensure that together we commission whole pathway services. Historically, it is acknowledged that there's been a lack of comprehensive commissioning of community services for this patient group across the entire region but this new joined-up approach has the potential to provide more comprehensive solutions as a system to meet the needs of the south west population as a whole.

One of the benefits of this programme is that we were able to harness senior clinical leadership, bringing senior clinicians on board at the very beginning. I think it's the coming together of these senior clinicians and the senior operational managers to co-design solutions that has been one of the key enablers of our success. There is a clear understanding that everything hangs on meeting the strategic aims, and if there's any deviation from that, there has to be a very clear clinical or patient-led reason why. This has turned commissioning on its head and put clinical drivers at the forefront of service re-design rather than financial or other aspects.



***At absolutely no cost to the health economy, we've commissioned a new 75 bedded secure service in our region.***

## PAULA HEAD

Chief Executive  
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST



Paula joined the trust as chief executive in September 2018, having been chief executive at the Royal Surrey County NHS Foundation Trust in Guildford and before that at Sussex Community NHS Foundation Trust. Paula began her career as a pharmacist working in the community, hospitals and at health authorities, before moving into general management and her first board position at Kingston Hospital. Since then she has spent time on the boards of commissioners and providers, including director of transformation at Frimley Park Hospital NHS Foundation Trust.

I am really proud to be chief executive of a hospital that combines an excellent district general hospital (DGH) with some superb specialised services. I feel no less excited by the DGH side of the business than I do by those services that can only be delivered in a specialist centre. The clinicians and frontline staff that work here do not differentiate either. Most of them work in standard DGH services as well as super-specialised and it is the cross over that engages them. I get quite vexed about the rhetoric that you can only get the level of care and outcomes that we see in Southampton, in London trusts.

### Creating interesting and varied roles for staff

I think that there is a direct correlation between staff involvement in the trust and the quality of outcomes for patients. Recently, our staff developed the trust's mission and reflected what it is like to work at University Hospital Southampton (UHS) in the words they chose: "University Hospital Southampton; together we care, innovate and inspire". People want to work here because it offers the variety that you get within a large organisation, with a mix of generalisation and specialisation. We make sure the environment allows them to have freedom to innovate, an opportunity to work with inspirational people in an organisation that cares about people – both patients and staff.

Increasingly, we are working and learning from the rest of the system, considering our patients as people holistically rather than a series of illnesses. This should prevent patients with long-term conditions 'bouncing' around between specialties. It is something we already do with a number of our specialised services where we care for the person, their family and carers in really difficult circumstances.


### Managing risk in a changing commissioning system

The differences between negotiating with local and specialised commissioners are not that great, although both have their tensions in managing the affordability of services with increasing demand.

These differences might become more apparent, however, as the changes in the commissioning landscape develop at different paces, with the move to population and blended payments happening more rapidly at local STP/ICS level than is realistic for specialised commissioning. We are worried about the impact of these changes on us as a large specialist provider with a DGH. For example, delegating specialist commissioning to an ICS without a large specialist hospital will impact on those systems with a hospital like UHS within its catchment. The size of the system footprint won't be appropriate for certain services.

It could mean that the commissioners that the provider has to deal with are fragmented and small – as are the populations that they commission for, meaning that some pathways that need extensively large populations may be at risk. It may be better to build it from the ground up – looking pathway by pathway to see what opportunities there are to share the risk.

The risk that exists for us comes from the difference between the current spend on specialised commissioning and the budget available to the commissioners. There is a danger that this is played out through ICSs, which are too small to hold that risk, passing it on to the provider. From a business perspective we cannot separate specialised from DGH service delivery so both the DGH and specialised services would have to take a hit – after all they are delivered by many of the same people, with patients quite often passing between the two.



***There is a direct correlation between staff involvement in the trust and the quality of outcomes for patients.***

In Hampshire and the Isle of Wight (HIOW) we are proposing a different solution. We are creating an integrated care partnership (ICP), which aligns with our STP principal that ICPs sit around the population of the acute trust. For UHS, this population is greater even than our STP at around three to five million and therefore needs to include other partners as well as those in our STP, e.g. Dorset providers, Salisbury and the specialised

commissioners for those populations. It will include our children’s hospital and support some of our wider networks beyond HIOW such as stroke, neonatal, pathology, radiology and support our genomics.

This population level feels like the right place to start because if we are going to make pathway changes to manage the specialised commissioning risk, it will need to involve these partners and we think if we do not have something like this in place our ambitions for change at this level may falter.

### Avoiding rushed contract changes

Originally there was a race to get HIOW to ICS status by April 2020. There are two reasons for not doing that – one is the size of this organisation, because if you want it to be meaningful on the front line, that means we have to bring 11,600 people to a different place in a few months. This is not realistic – we will need longer than this to bring our people with us and make any changes stick.

There is a huge opportunity for us to shift the dial on self-care, prevention and wellbeing, but this needs to be done with partners, patients and future patients, so you can get a population-level change rather than just a provider change. Also, at the moment, because the trust has operated



under payment by results so successfully over so many years, it will take a while to get the whole organisation to adjust its thinking.

We are working out with our commissioners, local and specialist, to figure out what the best way to move to a population budget might be. This has to take into account the interactive risk between the two types of commissioning, populations and the provider's ability to absorb the risk at the same time. This is why working together to solve the problems in our ICP, from a pathway perspective, is so important. Because of the CCG funding allocations, our population does not have the money the national formula believes it will need to meet their needs. Add this to the specialised commissioning risk I have described and you can see why we need to change at a reasonable pace. I am pleased that this year's tariff proposals recognise this with only two additional blended payment proposals.

Along with recognising the specialised/local commissioning issues for trusts like UHS we also need to have a national discussion about how the capital needed for specialist transformation will be recognised and made available in a way that supports pathway configurations at a level greater than ICS populations.

I am aware that regional and national specialised commissioners are working all of these issues through at the moment and I would urge them to engage with providers like ours, as well as fully specialist hospitals and those DGHs with some specialised services. This way we can work on delivering the long term plan solutions together.



***There is a huge opportunity for us to shift the dial on self-care, prevention and wellbeing, but this needs to be done with partners, patients and future patients.***



## JOHANNA MOSS

Director of Strategy and Business Development  
MOORFIELDS EYE HOSPITAL NHS FOUNDATION TRUST



Johanna joined Moorfields in July 2015. Her responsibilities include strategy development, capital investment and development, annual planning, business development, marketing and communications, external relations, and corporate and social responsibility. Before coming to Moorfields, Johanna was deputy director of strategic development at University College London Hospitals NHS Foundation Trust.

The shift to system working provides a great opportunity to bring local partners together with a mandate and a challenge to do something different. At Moorfields we are working with the primary care optometry sector and system partners at a regional and national level to improve both outcomes and peoples' experience of eye care in exciting and truly transformational ways.

The eye-care sector has its challenges, including fragmented commissioning, variation, and delays in accessing care. But it also has some enviable assets, not least the willingness of the sector to come together (for example through the UK Ophthalmology Alliance), the opportunity and the means to make clear advances (being the largest outpatient specialty), and often the ability to do this at pace (artificial intelligence, virtual clinics). Additionally, we hope that the work the eye care sector is now embarking on will provide a useful replicable model of collaboration that can be a catalyst for integration well beyond eye health.

### A population-based approach

At the moment, Moorfields and our partners are starting to have some really exciting conversations about how eye-care services could be commissioned across the whole population. We're in the early stages of discussions to help us try and understand what that model might look like and what the financial risks and benefits might be. These are big questions but, if we get it right, there is the potential to really transform the way patients receive eye care. Here at Moorfields, we are working on some really important interventions for older people, focused particularly on sight loss prevention, early diagnosis, treatment and support. We are confident this work will contribute to achieving the ambitions of the NHS long term plan in a very demonstrable way.

### The regional value-add

Moorfields is a specialist hospital with a local, regional and national outlook – though unlike many other specialist hospitals the majority of our work is commissioned by CCGs. The creation of the NHS England and Improvement London region offers a real opportunity for a clear commissioning voice for the capital that supports greater efficiency and reduces waste and duplication in the system. To date, our experience has been very focused at an STP level, which makes perfect sense for most NHS services. However, we provide services across eight different STP footprints, so a real challenge for us is ensuring we are working meaningfully across them all. There is some great clinical collaboration at STP level, bringing together providers and commissioners.



The added value the London region can bring for us is to provide a strategic framework for these collaborations and act as a real catalyst for widespread positive change.

### Seeing beyond competition

Most of us working in these new systems – clinicians, commissioners, community and hospital leaders – have grown up working in a competitive NHS environment. I think individually and organisationally it's important to recognise that adjusting to the new collaborative context and adopting the leadership behaviours to make it work is challenging, particularly when the new structures and processes are at an early stage of development. Creating the right context and support for local system actors is critical in allowing us all to work together, think differently and resist the temptation of resorting to our old transactional behaviours focused on the bottom line.

### The high street challenge

One aspect of system working in eye care, which is still at an early stage, is understanding how the high street, both independent opticians and large multi-national chains, will interact and align with a more collaborative NHS system. This 'high street to hospital' dynamic, shared with dentistry, actually shows very clearly that we work with and across a number of systems that are not as closed and controllable as we might like. It provides another challenge to creating shared incentives and the right behaviours. While there are a number of issues that need looking at, we think some of the solution lies in IT infrastructure improvements (sometimes as basic as making NHS email addresses available), so that clinicians across care settings can work effectively with patient data to provide responsive, joined-up and quality care.



***Creating the right context and support for local system actors is critical in allowing us all to work together, think differently and resist the temptation of resorting to our old transactional behaviours focused on the bottom line.***

### Harnessing the patient benefits of digital and innovation

Overall, this new environment has created lots of new opportunities for innovation and has given us the freedom to think differently. Our strategy places a clear emphasis on innovation and being a pioneer in discovering and developing new diagnostics and treatment models in eye care. In recent years, a key focus has been on how informatics and digital technology can act as an enabler for clinical decision-making as well as the shape of service provision. We've recently been awarded a Health Data Research UK bid, which is being led by the University of Birmingham, with partners including Google Deep Mind, patient organisations and other commercial organisations.





***Overall this new environment has created lots of new opportunities for innovation and has given us the freedom to think differently.***

It's a great example of where access to new funding sources are creating opportunities for us to explore and realise the potential of digital.

Particularly in ophthalmology, patients will be able to access advice and guidance without having to physically travel to an appointment. The impact of reducing the need for our patients to travel to us is huge. A significant proportion of our population are older and often living with some level of sight loss, so making sure we're only asking our patients to travel to an appointment when they absolutely need to is important. Wherever possible, we're bringing care closer to them and technology should enable us to do that more and more.



## JOHN MURRAY

Director  
FEDERATION OF SPECIALIST HOSPITALS



John is director of the Federation of Specialist Hospitals, which represents hospitals with a particular therapeutic focus, such as cancer or eye health. He was previously managing director of a consultancy specialising in healthcare policy.

People are not entirely happy with the current state of affairs regarding specialised commissioning, but there were some reasons for that in terms of the size of responsibilities transferred to NHS England, the limitations of the budgetary information that was given to them by the primary care trusts (PCTs) in their twilight period, and the fact that the commissioning resource in NHS England, as compared with the resource that had been available to the PCTs through their specialised commissioning groups, was considerably reduced. There were massively increased responsibilities and massively reduced resources. It almost inevitably became very transactional.

A lot of the dissatisfaction is a function of the situation we have been in over the last six or seven years since the Lansley Act [Health and Social Care Act 2012] came into force. It's not necessarily a reflection of how things could be in the future.

### Legislative framework for specialised commissioning

If you look at the conclusions drawn from the recent exercise around the need to change primary legislation, there is a categorical statement that NHS England will retain responsibility for specialised services. That doesn't mean that they can't work in a more creative way with local commissioners through ICSs and the like, but it does mean they will keep primacy and budgets. I think that's probably sensible.

Given the law as it stands, and given the results of the consultation exercise that NHS England has recently completed on potential changes to primary legislation, we have seven regional offices of NHS England that are potentially well positioned to mediate that relationship between specialised providers and local commissioners. Even more so, there is an opportunity for specialised providers to actually share their expertise with commissioners and where appropriate to deliver the patient pathway through specialities.

Under the law as it's likely to stand following that consultation, NHS England continues to hold the budget, but it can express the budget through those regional offices and the regional offices are in a good position to work with more local commissioning or collaborative entities.

The regional offices are brand new. There is an opportunity there, but it's very important we don't end up with a regional cacophony. The regional offices have the potential to mediate the relationship with the more local levels, but what I don't think we want is for them to reinvent stuff at regional level which is actually best determined at national level. Obviously, you've got the highly specialised services which have always been and should remain at a national level.



But things like service specifications, along with determining what is specialised, should remain at national level. However, there's a lot of latitude to determine how those services can best be delivered and that can be divided up between specialised and local providers.

The NHS tends to be a victim of fashion. It goes from one extreme to the other – one minute it wants everything to be ultra-local, the next everybody wants to run the NHS by national diktat. If we're honest with ourselves, it needs to be more nuanced, and I hope it will be. But there have been occasions over the last few years when there's been this very definite view that we've got to move to local population planning, and we know from experience that with many of the specialised services that isn't appropriate. I would hope there can be a sensible discussion and balance struck.

### Specialist trusts as national assets

We actually have national assets here in terms of healthcare delivery, but also in terms of the economic potential of the NHS. One of the really exciting things with the long term plan is to discuss how you can leverage the expertise of these national centres of excellence to diffuse innovation throughout the wider NHS. For that to happen, these centres need to be integrated with the wider NHS in a way which perhaps hasn't always happened in the past.

I think sometimes our member organisations are portrayed as ivory towers. They certainly don't want to be. They are very rooted in the NHS as a whole and we definitely want our services to be well-integrated within the wider NHS so they can do a good job for patients, but also be available to other NHS organisations to share their expertise and innovation. That's going to be very important, because we need to make the most of those opportunities.

### Potential of payment reform

I think that a block payment for a patient for a year of care has real potential, in part because it can incentivise new behaviour in delivering a good service for a patient. This is why you need to have outcomes in there as well, to deliver a high quality of outcomes but take advantage of new technologies.

If you do have a decent handle on how much care costs for patients with particular specialised conditions, there should be some opportunity to look at appropriate levels of tariff in a way which delivers good value but also generates opportunities for innovative approaches to care. As a federation we're very keen to see a good balance within payment



***One of the really exciting things with the long term plan is to discuss how you can leverage the expertise of these national centres of excellence to diffuse innovation throughout the wider NHS.***



methodologies vis a vis the outcomes that are being achieved. You'd expect us to say that because we believe our members deliver good outcomes and obviously delivering good outcomes is part of efficient care.

## NHS England's role in supporting joined-up thinking

As a specialised provider, you've got to be a member of an STP, but actually the enthusiasm of that STP to engage with a specialised provider, where that provider might have a large proportion of its patients coming from out of the STP area, is going to vary. That will vary between different providers and parts of the country, but it is an issue.

Historically, NHS England has been a bit reticent, and could maybe play a more constructive role in ensuring different parts are joined up – that would be helpful. Its one thing for providers of a particular service to establish a network, but it's another thing for that network to actually be fully integrated with the NHS at a local level, and we're very keen to see that linkage occur.

At the moment I don't think it's happening – or certainly happening as well as it could or should. That has been for slightly doctrinaire reasons, because the fashion has been a focus on local populations and planning. The danger there is that we leave specialised providers to greater or lesser extent out in the cold, which means as an NHS we're not getting the best value from them. Hopefully, that will change.

It's partly organic, but I think there does need to be a bit of input from NHS England so they've set a clear direction for CCGs in relation to STPs and ICSs. This need not be a grand strategy, but guidance in terms of how NHS England see specialised providers linking in with the local NHS so that the value of the relationship can be maximised.



***The danger... is that we leave specialised providers to greater or lesser extent out in the cold, which means as an NHS we're not getting the best value from them.***



## LOUISE PATTEN

Chief Executive  
NHS BUCKINGHAMSHIRE and NHS OXFORDSHIRE CCGs



Louise is the chief executive of NHS Buckinghamshire and NHS Oxfordshire CCGs and led on the successful bid for Buckinghamshire to become one of the first eight ICSs. Previously, she has board-level experience within NHS provider and commissioner organisations and worked for a commercial healthcare company. Louise maintains her nursing registration and has a strong patient-focused approach to commissioning services, recognising the importance of sustainable primary and community health and care, to support out-of-hospital transformation.

We work closely with Oxford University Hospital as a tertiary provider and with Buckinghamshire Healthcare Trust, which provides specialist spinal services. The movement to try and get local CCGs involved in specialised commissioning is relatively immature but we have clear plans to set up our ICS specialised commissioning planning board.

This isn't just about doing our bit of specialised commissioning for our population – specialised services have to be commissioned at scale. We don't want to lose the subject matter experts we currently have, but there is a need to develop the network of specialised commissioning. We should be further developing specialised commissioners to work alongside and in partnership with tertiary, secondary and primary care providers to really understand, technically and managerially, how best to commission that end-to-end service for populations.

### Ensuring specialised commissioning addresses clinical concerns

The biggest frustration I experience are the letters of complaint, often from the patients themselves, who are trying to get hold of their next prescription or their next episode of local care. We don't link up pathways very well for the person, either with their local district hospital or into primary care.

For example, prescribing for gender dysphoria starts with a tertiary referral. The consultant sees the patient and recognises they are suitable to start medication. There's often no need for that tertiary centre to see the patient for some time afterwards, so the referral for prescribing passes to a GP. The incidence of gender dysphoria in general practice is low so the GP may only see one or two patients during their career. They can be rather alarmed at having to support this patient psychologically as well as prescribing medication. There needs to be improved clinician to clinician links, so that clinicians in every care setting feel confident in what the plan of treatment is and are therefore happy to support the patient.

This is not a criticism of specialised providers – commissioners have got to look at the whole pathway. We need to describe what that end-to-end pathway looks like from a best practice perspective, but we don't do that very well, because specialised commissioning is segregated from local CCGs. Linking clinicians in tertiary centres to local hospital clinicians and out to primary care is key. Our specialised commissioners don't commission beyond the tertiary provider – that's why CCGs are keen to get involved.



## Embedding commissioning expertise in the regions

In terms of end-to-end pathway commissioning, I could see an approach where regions specialise in the commissioning of specific specialised services. This would involve working in partnership with providers to describe best practice in terms of planning care at every stage of the patient journey, through their tertiary referral and back into primary care. If we can get this right, there would be a coordinated approach in each of the regions, sharing their commissioned pathways across this new network of specialised and generalist commissioners. Regional commissioning would be a pretty good start, but let's not have all regions doing everything.



*In terms of end-to-end pathway commissioning, I could see an approach where regions specialise in the commissioning of specific specialised services.*

With the digital capability we have now, and with the information flows that allows us to develop further, we should be able to improve our patient engagement – many specialist patient groups have virtual online communities we could tap into to learn about real life experience of services.

If properly coordinated, then for a time we will need some national oversight to make sure everyone does get up and running. There are some services that require national level commissioning. These could also be handled at regional level, with specialised and local commissioners in partnership, as this would facilitate whole pathway oversight.

## Resolving tensions between investing in research and financial efficiency

Specialised services attract the benefits of research and development funding – clearly there is a benefit to local populations of having a nationally renowned tertiary centre in your local vicinity. Specialised commissioning spend tends to be higher for populations located closer to a tertiary centre.

Oxfordshire is overspent in terms of specialised commissioning activity, but when I speak to clinical colleagues, they say we will only enhance our progress in medicine, surgery, nursing and allied health professions by offering more of these opportunities and furthering our research. The question is who should pay for this activity? I think there's a question over whether, if we require research in this clinical area, research should be helping to support the funding of the patient activity. Simply reducing this activity (and cost) may inhibit our ability to develop healthcare research and innovation.



One of the challenges my local scrutiny committee has raised is about engaging the local public when commissioning specialised services. For example, a recent procurement of positron emission tomography demonstrated that while the contract decision affected relatively few people in Oxfordshire, any change in provider would have a much wider significance in terms of Oxford University Hospital's specialised services and research activity. The local scrutiny committee had not brought together other scrutiny committees to think about what the change meant. Working across regional areas might offer an opportunity for some lay representation or patient voice to be better heard.

I feel really positive that the direction of travel under the long term plan is absolutely the right one. The ICS approach will support this, because it looks at systems and at the experience of patients going through different providers on their pathways within the system. I just hope we manage to improve our end to end links for specialised commissioning, from tertiary through district hospital and into primary care. It isn't as black and white as being more efficient and trying to save a bit of money – we have got to address the issues around research and acknowledge the richness of what that brings us. It is ultimately one of the reasons why the NHS has the best and most innovative service providers in the world, and we mustn't lose that.



***We have got to address the issues around research and acknowledge the richness of what that brings us.***



## GEMMA PETERS

Chief Executive  
BLOODWISE



Gemma joined Bloodwise as chief executive in September 2017. Prior to this she worked at King's College London and King's Health Partners as executive director of fundraising and supporter development.

A lot of the treatments that blood cancer patients receive such as chemotherapy or CAR-T therapy (a form of immunotherapy) are considered specialised. Once people are in the system, the feedback we get is that services work pretty well. One of the biggest challenges is how they get into that pathway in the first place.

### Difficulties in accessing specialised services

The experience of blood cancer patients can be a little different to the experience of other cancer patients. There are over 100 different types of blood cancer. Blood cancer patients end up being seen in haematology clinics, not oncology clinics. That can mean they are less able to access some of the things available for other cancer patients and indeed patients with other conditions. A whole cohort of blood cancer patients are on 'watch and wait', where they've received a diagnosis but

aren't getting any treatment. They have significant needs in terms of their mental health and wellbeing.

We did a piece of research which found the variation across the country on access to psychosocial support for people with blood cancer is massive. 70% of men and 80% of women told us their diagnosis impacted upon their mental health, but over half received no specific emotional or psychological support from the NHS.

### Using specialist providers to support prompt diagnosis

Blood cancer is the fifth most common cancer and yet it is one of the slowest to be diagnosed, so there's a real issue with referral into the right place at the right time for these patients. Around 30% of people have seen their GP three or more times before they get referred for a diagnosis. A lot of the symptoms of blood cancer could be many other things. Access to specialists for GPs can make a real difference. If GPs can access a consultant in haematology to really talk through what they're seeing, that might take out six months of patients bouncing around the system and being in the wrong place. Before you even get into the specialist system, there needs to be some way of the specialist reaching into the community to pull those diagnostics through.

The NHS long term plan proposes the roll out of new rapid diagnostic centres. The reach of these might make a difference for blood cancer patients getting into the right service. But the aspiration is to diagnose the majority of cancers in stage one or stage two and staging data in blood cancer isn't at all effective. Staging data makes sense if you've got a solid tumour. In blood cancer, for all sorts of reasons, staging isn't a helpful measure in many cases and there sometimes isn't staging data at all.





## Navigating a rapidly changing clinical environment

Blood cancer is an area where the science and treatment are incredibly fast moving. There are a smaller number of patients whose conditions are demanding what is close to personalised treatment – there’s a sense that those treatments need to be commissioned nationally. As a charity we must then ask how do people afford the cost to travel there, how do they negotiate that longer period of absence from their work, and get the psychological support they need?

Nationally commissioned services have regional variation and the experience of someone in the south east or in an area where there’s big research led capability tends to be very different from other parts of the country. One of the ways that tends to come up is in access to trials. There’s huge variation in whether patients will be offered trials or offered the trials that are the most appropriate for their condition. That varies around the country and it’s an area of real concern for us.

Because science in blood cancer is moving so quickly, the other challenge that we hear about a lot is that there’s not one established treatment path – there are so many different choices that your commissioner is making for you. That can be overwhelming for cancer patients and they often feel that they have no agency in that decision-making process. Perhaps the most distressing point is end of life, where there seems to be a high occurrence of blood cancer patients not feeling like they were given all the information about the likelihood of treatments working.



***70% of men and 80% of women told us their diagnosis impacted upon their mental health, but over half received no specific emotional or psychological support from the NHS.***

## Ensuring patients have a voice in specialised services

In a blood cancer environment, partly because the patients can be so acute, and sometimes because there are just so many things you can keep trying, perhaps the patient voice isn’t being heard as it should be. We’re just starting a piece of work with Citizens UK to work with patients, clinicians and providers to see if there’s a way we can improve how that’s working for patients, because it’s really distressing for families.

Patients often say to us they feel they need to be the experts in their treatment, because no one else is and because they are moving between lots of different bits of the system and they are the ones that need to be asking questions. This becomes further complicated where there is comorbidity, and patients are concerned about the interplay between different medications.

Patients tend to have a better experience when they have a clinical nurse specialist (CNS), and yet the cancer patient experience survey tells us that



some blood cancer patients miss out on access to a CNS. We have a programme for educating and informing patients about how they can have conversations with their clinical leads, ask the right questions and feel confident in their agency in the system.

Some trusts are really good at involving patients in decisions about services, but when they are looking for cancer patients to involve, they go to the cancer centre or the oncology unit and often don't pick up blood cancer patients there. The experience of blood cancer patients can often be quite different, and we've seen an under-representation of these patients in established patient fora.

We have some examples of patients treated at organisations where they feel they have been really involved in discussions about their treatment, and also in the wider decisions of trusts about how they provide services. We work closely with NHS England to ensure that patients' voices are represented. There are some really good examples, but it isn't universal.

99% of patients would have no language to describe specialised care – it's just their health and their healthcare. The complexity of the system doesn't help patients to have agency – for instance, access to new treatments via the cancer drugs fund has been transformational for blood cancer patients. About a third of the treatments that have been approved are for blood cancer, so it's huge, but other than patient advocates who've got involved, I haven't met a patient who would understand that. The ongoing commitment to new and innovative treatment is really exciting and positive: having therapies like CAR-T right at the heart of the NHS, and recognising that being able to provide them is an important part of the NHS remaining loved and respected by the public.



***Patients often say to us they feel they need to be the experts in their treatment, because no one else is.***



## MATTHEW SHAW

Chief Executive  
GREAT ORMOND STREET HOSPITAL FOR CHILDREN  
NHS FOUNDATION TRUST



Matthew joined Great Ormond Street Hospital NHS Foundation Trust as medical director in March 2018 and was appointed chief executive in December 2018. He was previously deputy chief executive and transformation director of the Royal National Orthopaedic Hospital, and medical director in BUPA Health Services. A consultant spinal surgeon who has worked in the NHS for 22 years, Matthew is a passionate advocate for universal access to high-quality services and champions new ways of working, embracing technology and partnerships to advance care, research and innovation.

We know that if we continue with the current trajectory, specialised commissioning will likely run into very significant financial problems over the next two to three years. We've got ever increasing deficits in specialised services. Plus, there are new treatments coming online that can transform patients' lives, which the public is expecting us to deliver and we want to deliver, but these will increase the pressure on budgets.

### Challenges and opportunities of new technology

What we're seeing is an ever-expanding ability to treat people effectively via new technologies, but some of those technologies are phenomenally expensive. If you look at CAR-T cells [genetically engineered T cells for use in immunotherapy], patients who would have had very high

mortalities from recurrent cancers are now potentially curable with very expensive technologies where we alter and use cells to attack cancer within the body. We are only treating a few patients at the moment but the inclusion criteria will likely expand over time and it's a technology we think we can use in different areas.

With big data fuelling advances in translational research there are also increasing numbers of effective treatments sitting in the queue for commissioning approval. We can't afford to wait for a 'rubber stamp' when we know that one of these could save or improve a child's life, so we often treat children at our own financial risk. Many Great Ormond Street Hospital (GOSH) patients are affected by rare diseases, which need more personalised treatments, and these are naturally more expensive to develop.

In specialist healthcare, the cost of complexity is magnified by the more universal challenge of volume. Over the last 20-30 years, every westernised health economy in the world has faced growing demand for healthcare, so we have difficult choices to make. The honest conversation we need at a national level is whether we are willing to pay more taxes and spend a higher percentage of GDP on healthcare to fund these new treatments for an increasing population. Or if not, what services we have to withdraw from. In my view, really those are the only two options that you have. Yes, there is the efficiency argument and I accept we can do a lot better – but even the best efficiency programmes in the NHS are achieving 2.2%. Realistically these programmes will have no impact on suppressing the demand for high-cost treatments in specialised services.



## Achieving a successful transition to digital working

I am an orthopaedic surgeon by background and if I saw a new patient in outpatients, the hospital would earn about £130, with perhaps £90 for a follow-up. Offering a telehealth consultation instead would earn the hospital just £35.

The smaller price tag is based on a perception is that the telehealth consult is quicker, involves fewer people, and less space. But hospitals are still going to be paying their doctors, nurses and administrators to run these clinics. They will also incur additional costs for licensing, hardware and the infrastructure. Of course, we need to go through a proper design and assurance process to make sure any service changes will benefit safety, effectiveness and the experience of patients and families.



***What we're seeing is an ever-expanding ability to treat people effectively via new technologies, but some of those technologies are phenomenally expensive.***

We all know that accessing healthcare digitally could offer many benefits – delivering long-term cost savings, reducing the number of missed school days and limiting our environmental impact. All the more reason not to fall at the first hurdle by failing to invest in the changes required. Let's be clear about what the real costs are to make this work – an electronic patient record infrastructure that supports real-time data sharing across organisations, voice recognition, and new apps and wearables that empower patients and their families.

We need to upskill our workforce to innovate in this area, and have some buffering of the tariff so that our income doesn't drop by two thirds, but reduces slowly over a number of years. We can reduce our fixed costs and make ourselves more efficient – but that doesn't happen overnight.

## Making the STP approach work for specialised providers

In terms of the total NHS budget, £20bn is dedicated to specialised services and the system's been designed for the majority of healthcare services which are local. Now we're having to think around how to retro-fit specialist services into a new world of local systems.

The debate at the moment is do you have a specialised commissioning function or do you devolve that budget to these local care systems? At the moment we have one contract with NHS England. Only about 4% of our work actually comes from our STP. If the budgets were devolved to STPs or ICSs, we would have to contract with every single STP in the country.

There are some real pros of the STP model – just getting people together in a room to think collaboratively about this stuff starts to change their



attitudes on organisational sovereignty. Legislatively, we are set up to make sure our own organisations succeed, but the whole ethos of the STP is around the system succeeding. The downside of the STP model is the dynamic of wanting to hold onto everything we do in that geographical area. This is a major problem for GOSH because designing great, efficient services for smaller cohorts of patients with rare and complex conditions requires a national perspective.

I chair the procurement group for north central London, trying to look at what cross-organisational savings we could make across hospital boundaries. That's useful to us as we're exposed to those pressures, whether it's cleaning contacts or security. If you look at things like our back-office functions, there's a lot of crossover – the work might be different but the infrastructure to run it is the same. However, in terms of making a significant difference to patient pathways, the work of an STP is less relevant, because it doesn't address the needs of the 96% of patients who come to us from beyond north central London.



***The debate at the moment is do you have a specialised commissioning function or do you devolve that budget to these local care systems?***

### Public health role of specialist hospitals

Even though only a very small number of local children will be GOSH patients, the hospital still has an important role to play as a force for good in their healthcare. Despite being based in one of the world's richest cities, there are significant pockets of deprivation near to the hospital with high child-poverty rates, where children are suffering from poor health outcomes. Really importantly, we have committed to becoming a clean air hospital and we collaborate with partners across London to contribute to population-health interventions.

We host the north Thames paediatric network, which works across all providers in north London and particularly focuses on complex care in children and how we can improve their pathways. Our partners at the UCL Great Ormond Street Institute for Child Health host the National Institute for Health Research children and families policy research unit, which conducts research to support evidence-based policy development in areas from early intervention through to preventing adverse outcomes for really sick and disabled children.

However, the broader child health field is complex, with a bewildering array of national, local and international work going on – so identifying where best to focus our support is not always easy. Every STP has objectives for children – the Healthy London partnership has its own objectives, while NHS England has commissioned children's networks that have their own as well. There are various players in the system, all trying to achieve change that isn't aligned.



Historically, we have engaged with commissioners on designing services that treat diseases, rather than on strategies for prevention. But like other specialist hospitals, we have so much more to offer in terms of data and expertise to inform population health approaches. So it's great that the NHS long term plan has prioritised efforts to develop a meaningful national prevention agenda.


We know that we're not doing well enough to make sure kids are vaccinated against preventable diseases. And we know that interventions at an early age can have a massive impact on the length and the quality of people's lives. The problem is that the pay-offs from prevention are not instantaneous. You have to put in the intervention over a number of years before you get the outputs years later. In a system that's always focused on meeting the year-to-year total, it is very hard to make any significant long-term investment.

We've now got more children who are morbidly obese and less active than ever before. They are going to have diabetes and heart disease at a much younger age. That's why demand management in the current context is pie in the sky. Until you start to tackle that, you've got a tsunami of people with multi-morbidity which is now occurring in the 40-50s, whereas previously this was occurring in the 70s-80s. We need a prevention agenda which is appropriately resourced and tackles childhood obesity, which is going to be the killer of our time.



***Designing great, efficient services for smaller cohorts of patients with rare and complex conditions requires a national perspective.***





**NHS Providers** is the membership organisation for the NHS hospital, mental health, community and ambulance services that treat patients and service users in the NHS. We help those NHS trusts and foundation trusts to deliver high-quality, patient-focused care by enabling them to learn from each other, acting as their public voice and helping shape the system in which they operate.

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