

Specialised commissioning delegation

Learnings from the first six months, and lessons for the future

Introduction

In April 2024, Integrated Care Boards (ICBs) in the East of England, North West and Midlands took on new responsibilities for commissioning specialised services – a role previously held by NHS England (NHSE). From April 2025, all other ICB across the country will also take on these responsibilities.

The Specialised Healthcare Alliance (SHCA) has been speaking with stakeholders from across the system, including charities and ICB commissioners, to find out how delegation is impacting the delivery of services and shaping patient experience, and identify opportunities to continue making progress in 2025 and beyond.

We hope the learnings, conclusions and recommendations of our listening exercise can be used to help the remaining ICBs prepare for April 2025, as well as supporting NHSE regional and national teams to facilitate a smooth transition towards nationwide delegation of specialised commissioning.

Background

There are over 150 specialised services, which support people with a wide range of rare or complex health conditions, including rare cancers, genetic disorders, or complex medical or surgical conditions. Historically, these services have been commissioned at a national level by NHSE, but for some time NHSE has been working towards the delegation of commissioning responsibility to ICBs across England.

In April 2023, NHSE and ICBs began jointly commissioning 59 specialised services deemed 'suitable' for delegation through nine statutory joint committees (comprised of NHSE regional teams and ICBs) covering the entire population of England.



Read our [Guide to specialised commissioning in 2024/25](#) for more information.

Since April 2024, further progress has been made through the full delegation of commissioning responsibility for suitable specialised services to ICBs in the East of England, North West and Midlands. Following recent NHSE [board approval](#) on 5 December 2024, the remaining ICBs in London, North East & Yorkshire, South West and South East are due to take on this increased level of responsibility from April 2025. 11 services have been added to the initial list of 59 services deemed 'suitable' for delegation, bringing the total to 70. This leaves 104 services that will remain commissioned at the national level by NHSE, including all highly specialised services.

Although commissioning responsibility will be delegated to ICBs for 70 specialised services, accountability will remain with NHSE – meaning that national standards, service specifications and clinical commissioning responsibilities will continue to be set at the national level – to ensure national oversight.

About the listening exercise

In autumn 2024, six months on from delegation, the SHCA conducted a listening exercise to build a better understanding of how specialised commissioning delegation is working in practice, speaking to the following:

- **Three charity members** of the SHCA which represent patients accessing specialised services
- **Two commissioners** from ICBs that took on commissioning responsibility for specialised services in April 2024
- **One membership organisation** with a large network of ICB partners
- **One local collaborative** of providers and ICBs preparing for delegation

Our conversations sought to explore the experiences of ICBs and charity members of the ongoing delegation of specialised services and the impact on patient experience, discussing the opportunities that can be leveraged with greater specialised commissioning responsibility, as well as any challenges that delegation presents.

Findings

The following themes came through strongly:

- Delegation presents opportunities to join up patient pathways across different care settings
- There is a risk of unwarranted variation arising from the differing approaches to specialised commissioning across the country
- Charities are concerned about the challenges involved in engaging with ICBs post-delegation

These themes are explored in more detail below. We also draw on our findings to make recommendations for how future delegation can lead to tangible improvements in service delivery and patient experience.



Opportunities presented by a whole-pathway approach

A key positive of delegation highlighted in our discussions with ICB commissioners are the opportunities presented by gaining additional oversight across the whole patient pathway (in comparison to having specialised services siloed in previous commissioning arrangements).

Having all elements of a patient pathway joined up under a single commissioner – from screening and diagnosis through to specialised care – is seen as a key enabler for improving prevention efforts, and was highlighted as a focus of delegation for most ICBs. For example, in areas such as cardiac, having joined up disease pathways will allow commissioners to more easily assess opportunities for earlier intervention that may help prevent a patient's condition worsening to the point where specialised services are required. This should not take away from the fact that for many patients with complex needs – such as those with rare genetic diseases – specialised services will always remain essential. Therefore, the pursuit of prevention must be appropriately balanced with continued focus on the delivery of high quality care for all.

Commissioners are confident that delegation can enhance the experience of patients requiring specialised services. Although patients may not recognise immediate improvements in how they receive care, in the longer-term commissioners hope patients will benefit from better access to care and greater wrap-around support, in time driving improved health outcomes. Similarly, with a whole-pathway approach to commissioning, there are opportunities to consider where specialised

care can be delivered closer to home for patients – something that would not have been as easily achievable before delegation. ICBs will soon have more control over all elements of the pathway for patients that access specialised services, opening the door to refreshed models of care.

It is clear that delegation has the potential to support earlier intervention and more joined up care for patients – which can only be a good thing. Charities are supportive of the objective to integrate care across patient pathways and are keen to help ICBs in reshaping pathways to best fit the needs of patients. To realise the benefits described above, effective relationship building between providers, ICBs and NHSE regional teams will also be essential.

Recommendation: ICBs should capitalise on their new commissioning powers to identify opportunities for earlier intervention in the patient pathway, whilst also exploring ways to deliver more integrated care, closer to home for patients requiring specialised services.

Risk of unwarranted variation



It is apparent from our listening exercise that there is no ‘one-size-fits-all’ approach to delegation, with different ICBs and regions choosing their own priorities and projects to pursue. A certain amount of flexibility is welcome, as greater commissioning responsibility for specialised services should allow ICBs to respond better to the needs of their populations, but we heard concerns from charities that it also opens up the risk that patients may be impacted by unwarranted variation.

For example, it was highlighted that ICBs are generally enthusiastic about delegation and the opportunities it presents – but ICBs are also in a very difficult position, sometimes forced to grapple with a lack of headspace or capacity to take on delegation confidently due to the challenges presented by immediate operational pressures.

In this context, there is a risk that specialised commissioning might be inadvertently placed on the backburner of ICB commissioners’ priorities, especially if there is not a dedicated lead for specialised commissioning within each ICB. It is promising to see that in some ICB regions, there is a lead strategic commissioner belonging to one host-ICB whose role it is to coordinate each ICB’s approach to specialised commissioning across the region – but this is not seen consistently across the country. Therefore, it is increasingly important that NHSE national and regional teams continue to step in and offer specialist support and additional capacity where necessary throughout the delegation process and, crucially, beyond.

Despite delegation, not every specialised service will be available in every ICB footprint, and some ICBs will hold different expertise than others. For patients who need to access specialised services and expertise outside of their ICB footprint, worries remain around how their care will be coordinated across ICBs in a varied landscape. These concerns are particularly acute for rare diseases, where there are a limited number of specialist centres across the country, with risk of geographical variation in access to care. However, there is an opportunity to mitigate the risk of unwarranted variation by supporting the sharing of best practice and peer-to-peer learning between ICBs and providers to limit the impact on patient experience. NHS regional teams and the NHSE national team should play a role in facilitating information sharing between ICBs and providers, both within and between their footprints. It is also important to consider how coordination of care between specialised and highly specialised commissioned services beyond delegation, and NHSE should provide further clarification around how this will be managed.

We have heard of some ICBs taking the initiative to build connections, share learnings and align priorities across footprints, but this seems to be reliant on individuals within the ICBs driving this progress, and there are no formal mechanisms or guidance to encourage widespread uptake of

this approach across all ICBs. More should be done at the national level to facilitate information sharing across ICB footprints.

To ensure that variation in specialised commissioning in different ICBs does not impact patient experience, national oversight and assurance will be key. Although there are robust oversight and assurance arrangements at both the regional and national level to ensure ICBs are clear on their roles in line with national standards, we believe more can be done to mitigate risks of variation. This includes making data on outcomes for each individual service publicly available (i.e. quality dashboards), so that charities can also monitor any inequalities in patient experience.

Recommendation: NHSE national and regional teams should facilitate information sharing between ICBs and providers within and between footprints to mitigate variation in expertise and quality of care across ICBs.

Recommendation: NHSE should maintain robust oversight and assurance of local commissioning of specialised services and make any outcomes data publicly available to allow for wider monitoring of any unwarranted variation in patient experience.



Concerns around ICB / charity engagement

From the charity perspective, effective communication and engagement with national/regional stakeholders is seen as critical to ensuring that specialised services continue to meet patients' needs.

However, there are concerns around the lack of mechanisms or formal channels for communication and engagement between charities and ICB commissioners, especially given many charities have no existing relationship with ICBs. We have continually heard from our members that these concerns are magnified 42 times over when considering that, from April 2025 onwards, charities and patient organisations will have to monitor 42 different ICB footprints and respond to challenges that are facing patients in each of them. This is in stark contrast to previous commissioning arrangements, where charities engaged at the national level with a small number of individuals, and it will be a particularly difficult transition for charities with limited capacity or resource, which is often the case for those that represent patients with specialised care needs. The charities we spoke to raised concerns around how the lack of engagement or transparency from some ICBs limits their view of what is happening on the ground in each ICB footprint and creates barriers to holding them to account for the services they commission.

As ICBs begin to establish relationships with specialist providers and provider collaboratives through the delegation process, there is a window of opportunity to include patient voices in the fold at an early stage. One practical hurdle that would be easy to overcome is that many charities are still unsure of who is responsible for specialised commissioning in each ICB, so are not able to get in contact with them. In some cases, we have heard that charities face a “closed door” when engaging with ICBs, with no opportunity to start the conversation. This is not necessarily because of a lack of desire on ICBs' part; in fact, it is encouraging to note that during this project we have seen an appetite from some ICB commissioners to integrate patient and public involvement (PPI) into the delegation process. We would encourage ICBs to proactively reach out to charities, while also making contact details publicly available to make it easier for charities to contact the relevant commissioners within each ICB. Fostering these relationships will allow ICB commissioners to fill knowledge gaps that might exist early in delegation and gain a better understanding of their population's specialised needs.

NHSE should help to facilitate PPI at the local level and could explore different ways of supporting ICBs and charities to build relationships in the new commissioning landscape. For example, guidance for ICBs on how to work in partnership with patients and communities could be updated

in the context of the new arrangements for specialised commissioning to ensure the patient voice is central in future planning of services. Equally, NHSE should continue its efforts to facilitate PPI at the national level, through channels such as the Specialised Services Stakeholder Forum, the Patient and Public Voice Assurance Group (PPVAG) and involving the patient voice within clinical reference groups – amplifying these opportunities wherever possible. The SHCA will continue to collaborate with NHSE throughout delegation to support it in improving and enhancing PPI at the national level.

Recommendation: Each ICB should have a named lead for specialised commissioning to ensure local accountability and facilitate relationship building with external stakeholders, and their contact details should be publicly available.

Recommendation: ICBs should proactively integrate PPI within local planning for the specialised services throughout delegation, with support from NHS regional teams.

Recommendation: NHSE’s national team should continue to facilitate and amplify PPI opportunities at the national level.

Conclusion

It is clear that delegation has the potential to transform the delivery of specialised services, through joining up patient pathways and identifying new opportunities for early intervention – but there are also risks that need to be carefully mitigated against. The key to making delegation a success will be collaboration and commitment to the process. Collaboration between ICBs, providers and NHSE national and regional teams, and most crucially collaboration with charities as they hold the expertise, insight and patient voice that should be central in every ICBs’ approach to this process.

In our work on delegation to date, the SHCA has sought to help our members navigate the ongoing changes to the specialised commissioning landscape and we will continue to do so in this new era for specialised commissioning. As this listening exercise has reaffirmed, we must also continue to focus on supporting greater collaboration between all partners involved in specialised commissioning through delegation and beyond.

About the SHCA

The Specialised Healthcare Alliance (SHCA) is a coalition of over 130 patient groups organisations and charities who support people across the UK living with rare and complex conditions. Our work is funded by 10 corporate supporters. We advocate for better services for patients, keeping rare diseases at the forefront of the national conversation. The SHCA focuses exclusively on overarching policy and does not address individual therapeutic issues. The SHCA has no political affiliation and seeks to work across party lines.

For more information about the work of the SHCA, please visit www.shca.info or if you have any questions, email team@shca.info.

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