

Written evidence submitted by the Specialised Healthcare Alliance

The Specialised Healthcare Alliance (SHCA) is a coalition of patient groups, charities and corporate supporters with a strong record of campaigning on behalf of people with rare and complex conditions in need of specialised care.

1 in 17 people will be affected by a rare or complex condition at some point in their lives. We believe that access to high-quality specialised services is fundamental for a properly functioning NHS and a key criterion by which the NHS should be judged.

The SHCA has no political affiliation and seeks to work across party lines. The secretariat of the SHCA is provided by Evoke Incisive Health. More information about the SHCA can be found at www.shca.info.

Executive summary

The SHCA welcomes the opportunity to respond to the Health and Social Care Committee's inquiry, '*Integrated Care Systems: autonomy and accountability*'. The inquiry is particularly timely as Integrated Care Systems (ICSs) prepare to take on delegated commissioning responsibility for a significant proportion of specialised services from April 2023.ⁱ

Our response touches on a number of the Committee's questions but focuses on the issue of how the right balance can be struck between allowing ICSs the flexibility and autonomy they need to achieve their statutory duties, and holding them to account for doing so. We ultimately make three headline recommendations:

- NHS England (NHSE) should set out a timeline for updating service specifications, the precise steps it will take to ensure compliance, and how it will monitor the safety and quality of services that do not currently have clear national standards
- NHSE should publish detailed governance and accountability arrangements for specialised services, including clarifying the relationships between commissioners, providers, clinical leadership and Patient and Public Voice (PPV) forums
- NHSE should continue to work with patient organisations to develop its future approach to engagement, involvement and PPV representation

Response

About specialised services

1.1 Specialised services support people with a wide range of rare and complex conditions, for example rare cancers, genetic disorders and complex medical or surgical conditions.ⁱⁱ There are currently just over 150 specialised services,ⁱⁱⁱ benefiting hundreds of thousands of patients each year. The annual specialised services budget is approximately £20 billion (roughly 15% of the total NHS budget).^{iv}

1.2 In May 2022, NHSE published its [Roadmap for integrating specialised services within Integrated Care Systems](#). The roadmap confirmed that delegation of approximately 65 specialised services from NHSE to ICSs will begin in April 2023, subject to an ICS readiness assessment due to take place towards the end of 2022. All services will continue to have national standards attached to them and NHSE will continue to be the accountable commissioner for all specialised services.

1.3 The benefits to the system of more integrated commissioning are well understood, and it is recognised that more joined up tertiary, secondary and primary care has the potential to drive improvements in patient outcomes and experience. There is widespread support for NHSE's aim to enable systems to provide more holistic care to patients, while maintaining access to the high-quality expertise that those living with rare and complex conditions require.

1.4 There are, however, a number of questions regarding how the move towards more integrated commissioning – through the delegation of some specialised services to ICSs – will work in practice. With April 2023 fast approaching, urgent clarification is needed in four key areas:

- Suitability of service specifications
- Compliance with service specifications
- Governance and accountability arrangements
- Patient involvement and future engagement

Suitability of service specifications

2.1 Service specifications define the standards of care expected from providers of specialised services. NHSE has made it clear that all services will continue to have national standards, as set out in service specifications, attached to them.

2.2 We understand that NHSE is currently undertaking a programme of work to update both the methodology for producing service specifications and the content of service specifications. This is welcome – some service specifications date back to 2013 and will clearly not represent best practice by today's standards.

2.3 However, more information is needed regarding next steps. For example:

- Which service specifications will be updated and when?
- How will the patient perspective and experience be gathered to inform the update to service specifications?
- How will NHS England ensure that updated service specifications focus on the outcomes that are important to patients – what form of consultation will be carried out with patients and their representatives to input into the new service specifications?
- If NHSE is considering delegating services before the relevant service specifications have been updated, how will ICSs know what 'good' looks like and what impact could this have on patients' treatment, care and support?
- How will NHSE ensure that service specifications remain up-to-date and always reflect best practice?

Compliance with service specifications

3.1 Central to the success of the new specialised commissioning model will be ensuring that services meet clear national standards. Otherwise, there is a significant risk of creating a 'postcode lottery' for both access to and quality of care.

3.2 With this in mind and to provide further reassurance to external stakeholders, including patient organisations, NHSE should set out the mechanisms by which it will:

- Monitor compliance with service specifications and involve patients in this process (for example, through co-designing patient reported outcomes, quality of life and/or experience measures to capture what is truly important to them)
- Publicly share the results in a timely fashion to allow for external scrutiny
- Ensure best practice is shared and rapidly implemented across the country

3.3 Furthermore, there is confusion regarding how the safety and quality of services will be monitored where there is either no service specification in place or the level of detail contained within the current service specification is inadequate. This is a particular issue for the most rare and complex conditions.

Governance and accountability arrangements

4.1 NHSE has stated that it will always retain ultimate accountability for specialised services, including those services commissioned by ICSs. This is welcome; however, more detail is needed on the governance and accountability arrangements that sit underneath this.

4.2 We understand that NHSE is in the process of developing an assurance and oversight framework for direct commissioning, including for specialised services, aligned to the System Oversight Framework (SOF). It will seek assurance that systems have the right capacity and capability, that statutory duties are being met, and that national standards and service specifications are being adhered to.

4.3 In addition, NHSE has shared plans to establish a Delegated Commissioning Group (DCG) for those specialised services delegated to ICSs. The group will manage the approval of national standards, approve gateways for national transformation programmes, guide support to regions and ICBs, and provide oversight of relevant specialised services.

4.4 NHSE should publish more detail on governance and accountability arrangements as soon as possible. This should include clarity on the steps that will be taken if an ICS, or a provider within an ICS, is found to not be meeting national standards. NHSE should also clarify the relationships between NHSE, ICSs, clinical leadership such as Clinical Reference Groups (CRGs) and clinical networks, exiting PPV forums, and provider collaboratives/providers.

Patient involvement and future engagement

5.1 We greatly appreciate NHSE's continued commitment to PPV representation. Areas where the SHCA believes more detail would be beneficial include:

- Explaining whether NHSE's accountability for specialised services extends to ensuring proper involvement of patients in ICS decision-making, including the involvement of patients with rare and complex conditions where appropriate
- Clearly highlighting the reporting lines of existing PPV forums such as the Patient and Public Voice Assurance Group (PPVAG), Rare Diseases Advisory Group (RDAG), Clinical Priorities Advisory Group (CPAG) and CRGs
- Identifying and sharing examples of ICSs successfully involving patients in their decision-making, highlighting the positive impact on service development and delivery

5.2 Furthermore, many patient organisations have set up regional/local networks comprised of clinical and patient representatives to raise awareness, identify and tackle gaps in

care, and upskill healthcare professionals (for example, Muscular Dystrophy UK's [Regional Neuromuscular Forums and Clinical Networks](#)). It is recommended that NHSE maps these networks and ensures that they are linked up with the relevant ICSs.

5.3 For the remainder of 2022/23, NHSE is planning to confirm the list of services to delegate to ICSs from April 2023, develop a framework to assess ICS readiness to commission these services, and publish a future assurance and oversight framework and revised governance arrangements. We would welcome further information on the opportunities to engage in this work, for example the development of clear and patient-focused metrics to be incorporated into the assurance and oversight framework.

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ⁱ NHS England. *Roadmap for integrating specialised services within Integrated Care Systems*. May 2022.

Available from: <https://www.england.nhs.uk/wp-content/uploads/2022/05/PAR1440-specialised-commissioning-roadmap-addendum-may-2022.pdf>. Accessed July 2022

ⁱⁱ NHS England. *Specialised services*. Available from: <https://www.england.nhs.uk/commissioning/spec-services/>. Accessed July 2022

ⁱⁱⁱ NHS England. *Manual for Prescribed Specialised Services 2018/19*. September 2018. Available from: <https://www.england.nhs.uk/wp-content/uploads/2017/10/prescribed-specialised-services-manual.pdf>. Accessed July 2022

^{iv} NHS England. *Allocation of resources to NHS England and the commissioning sector for 2019/20 to 2023/24*. January 2019. Available from: <https://www.england.nhs.uk/wp-content/uploads/2019/01/04-pb-31-01-2019-ccg-allocations-board-paper.pdf>. Accessed July 2022