

Subject: Urgent Clarification Regarding NHS England Reintegration and Services for Rare and Neurological Conditions

Dear the Rt Hon. Wes Streeting MP and Sir James Mackey,

On behalf of our collective membership of over 200 organisations, Genetic Alliance UK, the Neurological Alliance, and the Specialised Healthcare Alliance are writing to highlight the potential implications of the proposed reintegration of NHS England into the Department of Health and Social Care (DHSC) for individuals affected by genetic, rare, undiagnosed, and neurological conditions.

We would welcome the opportunity to work with you during the transition period to ensure that the reforms deliver for people who use health services. In the short term, the reported scale of this reorganisation has generated considerable concern within our communities on the future of services crucial to their care. We are writing to request urgent clarity in several key areas:

Ensuring continued commissioning expertise

We welcome the recent clarity from NHS England that the commissioning of specialised services will remain uninterrupted in the short term, and that it will remain the accountable commissioner of specialised services delegated to Integrated Care Boards (ICBs).

In the longer term, our members are deeply concerned about the potential impact of budget and staffing reductions on the availability of commissioning expertise. To ensure the commissioning of specialised services is not negatively impacted by these reforms, it is important that commissioning expertise is protected as NHS England is integrated into the DHSC. NHS England's decision to maintain commissioning responsibility for 80 highly specialised services reflects the complexity of these services and the importance of maintaining specialist knowledge in their commissioning.

We have already received inquiries from our members regarding the future of many specific specialised services. We note with interest your recent comments that as part of reforms the right level for commissioning different specialised services will have to be reconsidered. It is important the Department sets out how it will ensure the uninterrupted operation of these services during the transition, and its vision for future commissioning – including any proposed changes to the level at which different services are commissioned.

Maintaining robust clinical leadership

The role of National Clinical Directors (NCD) and National Specialty Advisers (NSAs) in areas such as Adult Neurology and Neurosurgery and Spinal Surgery within NHS England provide crucial clinical leadership in driving service improvement and transformation. Losing such expertise at the highest level of decision-making at the same time as specialised services are delegated to ICBs would be detrimental to the provision of effective care for our communities. It is vital that strong clinical leadership within the evolving structure is maintained.

In addition to NCDs, NHS England's wider infrastructure for providing clinical leadership as part of commissioning plays a vital role in ensuring high quality services. These include National Programmes of Care, which coordinate work across the services they cover, and Clinical Reference Groups (CRGs), which help to ensure services are commissioned consistently in line with national service specifications and commissioning priorities.

CRGs also play a vital role in driving forward transformation programmes and providing timely clinical advice, which are key in advancing patient outcomes and experience. It is important clarity is provided on how NHS England's clinical infrastructure will be protected and built on by the Department, so that commissioning expertise is maintained, and local systems are supported to commission services in line with national priorities whilst meeting local population needs.

Progressing the delivery of a robust foundation for rare disease data and genomic medicine

The role of critical infrastructure to deliver significant advancements in the understanding, diagnosis, and treatment of disease are key to delivering the most effective healthcare for people with genetic, rare, undiagnosed and neurological conditions.

Our community are concerned that the extent of NHS England reform risks destabilising important progress in critical areas for genomics as set out in the Life Sciences Vision. For example, the Genomic Medicine Unit, which is in a vital stage of 'mainstreaming' genomic medicine into broader care, faces uncertainty and the future of vital NHS Genomic Networks of Excellence is unclear. Similarly, the National Disease Registration Service (NDRS), essential for data collection on rare conditions and healthcare efficacy, requires urgent clarification on its future funding and staffing to avoid disruption. It is important that this infrastructure is maintained as a priority to harness the UK's unique genomic data and facilitate advancements in the delivery of care for people with genetic, rare, undiagnosed and neurological conditions.

We ask that clarity is given on how this infrastructure will be transferred with limited disruption to the delivery of services so that technological advancement can be facilitated and delivered in healthcare.

Guaranteeing Patient and Public Voice in decision-making

It is vital that the voices of those living with genetic, rare, undiagnosed, and neurological conditions are heard and integrated into the new decision-making processes that will emerge from this reintegration. Our communities need clear avenues to engage with these processes to ensure their needs and experiences inform service design and delivery. Understanding how patient and public involvement will be structured and maintained throughout this period of reform, building on NHS England's patient and public voice partners, is essential to ensuring services meet the needs of people with genetic, rare, undiagnosed, and neurological conditions.

UK Rare Diseases Framework

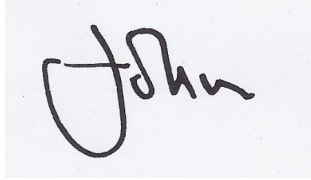
The UK Rare Diseases Framework has been a valuable vehicle for driving progress across the areas outlined above, fostering collaboration between the community and delivery partners and setting clear priorities for improving the lives of people living with rare conditions. As the proposed reforms are implemented, it is now even more vital that this Framework is renewed and strengthened to maintain momentum and ensure continued progress against its four priorities.

We ask that you meet with us to discuss how this transition can be delivered whilst maintaining high standards of care for individuals living with genetic, rare, undiagnosed, and neurological conditions. We look forward to your prompt response and a commitment to engaging with our community throughout the process of reintegrating NHS England into the DHSC.

Yours sincerely,

A handwritten signature in black ink that reads "N. Meade". The signature is written in a cursive, flowing style.

Nick Meade, Interim Chief Executive, Genetic Alliance UK



Lord Sharkey, Chair, Specialised Healthcare Alliance



Georgina Carr, Chief Executive, The Neurological Alliance



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