

Written evidence submitted by the Specialised Healthcare Alliance (HSC0881)

Executive summary

The Specialised Healthcare Alliance (SHCA) is a coalition of more than 100 charities and corporate supporters campaigning on behalf of people with rare and complex conditions in need of specialised care.

The SHCA believes that the forthcoming health legislation presents an opportunity to embed mechanisms and standards that will deliver equity in access to high quality care for people with rare and complex conditions. This submission sets out ten areas in which improvements can be made, based on engagement with the SHCA's charity members. Detailed points for each area have been provided to support the Committee's inquiry and its scrutiny of the Department of Health and Social Care's proposals.

Suggested areas of focus

1. Safeguarding minimum national standards of care for people with rare diseases, and supporting continuous improvement in patient outcomes

- The NHS White Paper was preceded by NHS England's proposals to devolve greater responsibilities and resources to Integrated Care Systems (ICSs). Building on those proposals, the White Paper sets out plans to enable NHS England to delegate or transfer the commissioning of certain specialised services to ICSs
- SHCA members have expressed concerns that delegating the commissioning of specialised services to the ICS level could lead to geographical variations in care, while the transfer of responsibilities could also create uncertainty over accountability for delivering high quality care
- The SHCA welcomes the commitment set out in the White Paper that all specialised services will continue to be subject to consistent national service specifications, as well as the Secretary of State's update that the DHSC will work closely with the CQC and NHSE to develop an oversight mechanism
- However, further clarity is needed on how oversight will work in practice, what safeguards on care standards will be included in the legislation, and how patient groups will be consulted on in the development of standards. We recommend that the Committee scrutinises this commitment and how it will be delivered, including what additional measures will be put in place to hold ICSs to account for continuous improvement in outcomes for specialised services. It is also important that delegating the commissioning of some specialised services to ICSs does not lead to increasingly fragmented care for people with complex co-morbidities

2. Establishing clear mechanisms and assurance processes through which specialised commissioning budgets can be delegated to ICSs

- NHS England has proposed that ICSs should be put on a clear statutory footing, but with minimum legislative prescription, and maximum local flexibility to determine appropriate 'place-based' arrangements
- The SHCA understands the importance of local involvement in, and ownership of, new arrangements for specialised services. However, there is a need for additional detail on how the Government will ensure clear mechanisms and assurance processes are created through which specialised commissioning budgets can be delegated to ICSs, and what safeguards will be in place to guarantee existing levels of spending on specialised services will be protected. It is

important that specialised commissioning budgets are only delegated where there is a strong case for doing so to improve services

3. Embedding the voice of people with rare diseases in ICS decision-making processes

- The White Paper states that a new ‘duty to collaborate’ for NHS bodies will be introduced, to encourage partnership working across the constituent members of ICSs
- Patients and third sector organisations have a high level of expertise relating to specialised services – they see most clearly the strengths and weaknesses of current arrangements with respect to issues that better integration is intended to address, such as continuity of care, access to local services and gaps in provision. It is therefore essential that patients and third sector organisations are viewed by ICSs as partners in decision making processes and are formally covered by the duty to collaborate

4. Creating minimum waiting time standards for the diagnosis of people with rare conditions

- For people with rare diseases, getting the right diagnosis is key to the appropriate management of their condition – as recognised by the UK Rare Diseases Framework published in 2021. However, getting correct and timely diagnosis continues to be one of the most significant challenges faced by the rare disease community
- The forthcoming legislation presents an opportunity to address this challenge by introducing a minimum waiting time standard for the diagnosis of rare or less common conditions, to increase accountability and improve diagnosis rates. This approach would be in line with existing standards for cancer care and would support the DHSC’s ambitions for improving care for rare conditions and provide direction to the wider efforts to recover diagnostic services in the aftermath of the pandemic

5. Establishing a new NICE assessment route to assess medicines for people with rare diseases, with improved mechanisms to engage with people with rare diseases, and faster timescales

- NICE is carrying out a review of its methods and processes and has made a series of initial proposals that could support more flexible assessment of treatments for rare conditions, such as the acceptance of a greater degree of uncertainty. While the SHCA welcomes these proposals, we do not believe that they go far enough to address the challenges that are associated with traditional HTA approaches for rare disease treatments
- NICE has indicated that it is beyond the scope of the review to make the changes that would be required, including the development of a specific assessment pathway for rare disease medicines. There is a need to consider how these could be taken forward through an alternative mechanism, such as legislation, in line with the approach taken to the creation of the Highly Specialised Technologies appraisal programme in 2012

6. Increasing awareness of rare diseases among healthcare professionals

- The recent UK Rare Diseases Framework included increasing awareness of rare diseases among healthcare professionals as one of its four priority areas. We recommend the Committee emphasises the importance of underpinning this ambition with concrete mechanisms to deliver improvements and seeks clarity on whether the DHSC plans to include provisions within its legislative proposals on reforms to workforce training

7. Mandating access to a named clinical nurse specialist for people with rare conditions

- Clinical nurse specialists are experts in evidence-based care for patients with complex needs. They play a key role in coordinating care, acting as a ‘key worker’ supporting patients through their interactions with the NHS and providing specialist advice
- Significant progress has been made in supporting access to clinical nurse specialists for patients with cancer in recent years, but gaps still exist for patients with rare and complex conditions. The passage of legislation presents an opportunity to set standards for access to specialist support for patients with rare diseases to support equitable access to high quality care

8. Making the uptake of treatments for people with rare diseases equivalent to the best healthcare systems in the world

- Advances in science offer the potential to improve the lives of people living with rare and complex conditions. There are many new medicines on the horizon that could offer hope to people with previously untreatable diseases. The SHCA welcomes the progress that has been made in speeding up the introduction and adoption of new treatments in recent years and the prospect of continued improvement through initiatives such as the Innovative Medicines Fund and the Innovative Licensing and Access Pathway
- It will be important that these initiatives are supported by clear metrics to assess progress. The forthcoming Bill presents an opportunity to embed targets for the system to deliver levels of adoption in line with the best healthcare systems in the world

9. Ensuring all patients with rare conditions are offered genomic sequencing by 2024

- In September 2020, the UK Government published its Genomic Healthcare Strategy – *Genome UK: the future of healthcare*. The strategy forms part of the NHS Long Term Plan ambition to sequence 5 million genomes by 2023/2024. It sets out how the genomics community will collaborate to harness genomic science, research and technology to improve patient care
- The SHCA welcomes the commitments made in the Genomic Healthcare Strategy, which will be key in realising the Government’s ambitions for improving rare disease care. The forthcoming bill presents an opportunity to strengthen accountability for the delivery of the target and to ensure that all eligible patients with rare diseases are offered genomic testing

10. Supporting access to COVID-19 vaccines, in particular for those with rare and less common conditions

- The Committee may also wish to raise issues highlighted by SHCA members over the COVID-19 vaccine roll out, including:
 - The absence of clarity on levels of uptake of the vaccine among those shielding
 - The lack of clear national guidance on the suitability of different vaccines for specific patient populations, such as those currently taking immunosuppressant drugs, resulting in varying guidance provided by healthcare professionals
 - The dissemination of vaccine misinformation by a small number of healthcare professionals, which may impact vaccine uptake among people
- The Committee may wish to note that while it is important for specific issues to be addressed immediately, it is important that the DHSC sets out whether the Government will seek to include any provisions in legislation regarding access to vaccines to mitigate against these challenges recurring in future