

JDRF Written Evidence Submission to the Health and Social Care Select Committee - Department's White Paper on Health and Social Care

Summary

JDRF is the world's leading type 1 diabetes research charity. It funds research to cure, treat and prevent type 1 diabetes.

JDRF welcomes the government's proposals for a new Health and Social Care bill, building on the NHS Long Term Plan. This provides a vital opportunity to remove barriers that people with type 1 diabetes face in accessing treatments. JDRF particularly supports the proposals within the White Paper regarding investing in improved data systems and technology, which will fundamentally improve patient experience both within the NHS and managing their conditions at home.

Our aim for this submission is to ensure that patient voice is recognised and promoted within healthcare reforms, so that everyone with type 1 diabetes can access informed, personalised and equal treatment. Health inequalities remain a consistent barrier for people in the UK, something which has been put under the spotlight during the coronavirus pandemic. This bill provides a key opportunity to address these inequalities.

This evidence submission is based upon conversations with people affected by Type 1 Diabetes, their families and friends, as well as clinicians and sector organisations. It builds upon the recommendations made in our [Pathway to Choice](#) report, published in November 2019.

These conversations have lead us to a number of recommendations for points of focus this Bill must address:

1. Addressing boundaries patients may face in accessing treatment, especially those from a lower socioeconomic group, along with the postcode lottery with regards to access to diabetes technology.
2. People with type 1 diabetes need more time with specialist healthcare professionals at their appointments, as well as improved training for NHS staff in type 1 technology to help people manage their conditions in the way most effective for their lifestyles.
3. Data from people with type 1 diabetes and their technology must be better collated, in order to improve both treatments and research into the condition.

Key issues to consider

Integrated Care Systems

JDRF welcomes the introduction of Integrated Care Systems across the country in order to foster a collaborative approach, but as has commonly been identified throughout the development of this bill, more detail is needed; specifically regarding how this merger will

affect people with type 1 and their families, as well as other such autoimmune or rare diseases. As part of this, it is essential to ensure that ICS's offer consistency among treatment and specialist centres. We have seen from National Diabetes Audits that some CCGs historically perform better than others, and integration provides the opportunity to learn from one another and improve services comprehensively. The proposals to introduce an Ofsted-style rating are extremely promising. Since these oversight mechanisms would include a summary rating for ICSs and would be underpinned by full data sharing, regional disparities can more easily be identified and best practice can be observed. JDRF welcomes this proposal as it will be essential in addressing both health inequalities and delivering consistent treatments, preventing the postcode lottery of accessing appropriate treatment for type 1 which currently exists.

Systems must be put in place throughout the mergers to ensure staff have the facilities and time to spend with patients, in order to properly provide them with an informed choice regarding their healthcare. Patient choice is recognised as a key factor for improving healthcare within the White Paper, as the department aims to *“work closely with the NHS to reduce the health inequalities currently experienced in the area of choice, by helping to increase clarity and awareness of patient choice rights within systems and of the range of choices available”*. This can be facilitated through ensuring clinics are accessing and offering new technologies to all patients, after an informed discussion. The paper also states that *“specialised commissioning policy and service specifications will continue to be led at a national level ensuring patients have equal access to services across the country”* which JDRF welcomes.

Training and Education for NHS staff

In order to ensure patient choice, JDRF recommends that the NHS should provide protected time for training of healthcare providers on type 1 technology and its funding pathways, while also taking into account shift patterns and agile ways of training. From this, details of clinics with trained specialists should be made publicly available, so that people with type 1 diabetes can be confident in approaching their clinician about technology.

The majority of people with type 1 diabetes whom JDRF surveyed as part of the Pathway to Choice report stated that they received information on their condition primarily through their specialist healthcare team, and diabetes specialist nurses play a significant role in encouraging the use of new technologies. Hence it is vital that all healthcare staff who interact with people with type 1 are knowledgeable and trained in new treatments in order to better facilitate patient choice.

Technology and data

JDRF are encouraged by the government's initiatives in improving the use of technology and data sharing. JDRF recommends that the government creates a national diabetes register, modelled on Scotland's SCI-Diabetes. This would have several functions including mapping type 1 technology uptake, providing regional statistics regarding health outcomes, and empowering clinicians to see patient data in one system. With a wider breadth of information and data on diabetes technology and patient experience, which can be shared across the UK, researchers and healthcare providers will better understand how the condition can be better managed, as well as identifying common problems which occur among patient groups and regions. This runs alongside the proposals for the use of technology in people managing

their own conditions - the data from which can be shared with their GP and used to ensure the individual is receiving the most suitable treatment available to them.

The proposals in the paper to “*allow the MHRA to set up registries themselves, and work with NHS to populate and maintain them where there is a clear patient safety or other important clinical interest*” are positive, given they further promote patient involvement through providing an opportunity for “*patients to actively contribute information on their experiences with specific medicines bringing focus to the safety and clinical effectiveness issues that impact most on their lives.*” Patient involvement is essential and the value of patient voice in assessing new and existing medicines and treatment must not be overlooked.

The pandemic has also provided more accessibility of virtual treatment methods, which will be essential in improving patient access to treatments and time with specialised clinicians in the future. This should continue and be promoted as an option going forwards in order to overcome boundaries - geographic, socioeconomic, or logistic - to treatment.

Conclusion

JDRF broadly welcomes the proposals put forward in the Health and Social Care White Paper. However more clarity is needed regarding how these proposals will impact people with type 1 diabetes, as well as their families and carers.

This bill provides a chance to reduce health inequalities across the UK, to improve practice comprehensively, and ensure that providers are delivering the best, most suitable care for their patients. This involves improvements in specific type 1 diabetes training among healthcare providers, as well as more time at appointments for people to thoroughly discuss their options and make personalised treatment plans.

Furthermore, the focus on data sharing provides a tangible opportunity to improve research into type 1 diabetes treatments, as this will enable GPs, researchers, technological developers and most importantly, the patients themselves, to identify commonalities across the UK within their treatments, which can consequently be used to improve knowledge of the condition and develop new treatments as a result.

For further information please contact our Public Affairs Team by emailing Rachael Crisp, Policy and Public Affairs Manager at rchrisc@jdrf.org.uk