

Written Evidence Submitted by JDRF to the Public Bill Committee - Health and Care Bill

Executive Summary

- **Patient Choice** - True patient choice can only come through widened availability of treatments to more people. The bill should include a provision to regularly train all healthcare providers in diabetes technology so they can feel confident prescribing it to patients, giving people with type 1 diabetes an informed choice of options. Integrated Care Systems should also make publicly available a list of clinics with trained specialists in their area. This should also give greater weighting to patient reported outcomes and impact on quality of life and mental health when prescribing treatments for type 1 diabetes.
- **Health inequalities** - Health inequalities between people with type 1 diabetes have been further exposed by the covid pandemic. The bill should include a provision for Integrated Care Systems to hold regular reviews of their patient population and identify areas where support may be lacking, for example in access to technology amongst ethnic minority or socially deprived groups. NHSE's System Oversight Framework for Integrated Care Systems should include a metric on the percentage of type 1 patients in their area accessing technology.
- **Accountability** - Integrated Care Systems must be primarily accountable to those they serve, namely their local patient population. This should be upheld, through patient representation on Integrated Care Boards.
- **Medicines Registries and Data** - The bill should go further than the introduction of medicines registries, to include disease or condition-specific registries. This aligns with the Draft Data Strategy and Life Sciences Vision, which embrace the power of data to support health outcomes and research into treatments for conditions such as type 1 diabetes. A type 1 diabetes register such as SCI-Diabetes in Scotland should be introduced across the UK, to share UK-wide information to support patient outcomes and research purposes.
- **Innovation** - The bill must go further to empower the NHS to be at the heart of innovation. It should promote recruitment into active clinical trials into innovative new treatments for type 1 diabetes. It should also identify patients who would benefit from access to new technologies and ensure that clinicians are offering new technologies to their patients with type 1, where appropriate.
- **Integrated Care** - The bill should support integrated care, where a person's multiple needs are managed in an appropriate setting. The bill should introduce measures to avoid people having to repeat themselves at appointments with clinicians, for example through shared records with different health teams. Mental health support should also be integrated and embedded within all type 1 diabetes clinics.

Introduction

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

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 evidence submission is based upon conversations with people affected by type 1 diabetes and their families, as well as clinicians and sector organisations. It builds upon the recommendations made in our [Pathway to Choice](#) report, published in February 2020.

Background

The Covid pandemic has demonstrated strengths and weaknesses within the NHS, and areas where systems can be reformed to deliver more equitable and better outcomes for patients. JDRF supports the aim to provide better health outcomes overall, yet people with type 1 diabetes must not be forgotten as the UK recovers from the Covid pandemic. Around 400,000 people in the UK have type 1 diabetes, and many of these will have been significantly impacted by the pandemic, with disruptions to routine care, as well as potential long-term complications that were not identified due to missed screening appointments.

Person-Centred Care & Patient Choice

JDRF welcomes the introduction of Integrated Care Systems, but more information is required specifically regarding how this merger will affect people with type 1 and their families. 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. Accountability and oversight mechanisms should include a summary rating for ICSs and would be underpinned by full data sharing, so that regional disparities can more easily be identified and best practice can be observed.

The bill preserves the right for patients to have a choice in their healthcare, for example in choosing a GP and GP Practice, as well as the location of appointments. This is crucial, and must remain one of the central focuses of the bill as it progresses. This is especially beneficial for people with type 1 diabetes. Many people with type 1 across the UK experience a postcode lottery when accessing treatment, meaning that they are unable to get, for example, an insulin pump due to their local clinician's lack of knowledge to prescribe them for patients.

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. Details of clinics with tech-trained specialists should also be made publicly available, so that people with type 1 diabetes can feel confident in approaching their clinician about technology.

It is also important that people have sufficient time at appointments to hold discussions with their clinician as to which option may best suit their needs, through assessing both their medical history, as well as their personal priorities going forward. Much of diabetes treatment currently involves assessing clinical outcomes and measures such as a person's history of glucose levels, determining if they have been consistently high, low or fluctuating between both. In the future, it is important that the priorities of the person with type 1 diabetes is also given stronger weighting, as not every person living with type 1 will have the same wants and needs, and even throughout one's own lifetime, their priorities may change. People with type 1 diabetes need to be able to make an informed decision that can support their lifestyle, which can be re-evaluated when necessary at appointments.

The bill must go further in centring the voice of lived experience at the heart of the NHS. In the development of Integrated Care Boards, there is value in providing a role for patients, in order to entrench them formally within organisational structures. Patient involvement must go stronger than limiting this to consultations with patients and carers, so that the NHS can promote collaboration and partnership in care.

Integrated Care Structures also must ensure accountability to local people, and ensure that all patients can benefit from commissioning decisions and have access to equitable treatment options. Accountability must also come through rigorous inspection procedures and regular reviews of the impact on patient reported outcomes from decisions and processes.

Health inequalities

The government needs to pay special attention to reducing health inequalities as this is already a significant challenge in today's landscape. Not everyone who wants to is able to access what diabetes technology is already on the market. JDRF's Pathway to Choice report identified a number of factors that can impede uptake, including location, time since diagnosis, and clinician willingness to prescribe, to name a few. Many healthcare professionals are reluctant to prescribe diabetes technology due to lack of training, meaning some people with type 1 face a postcode lottery in access to treatment, lacking choice and power over one's own healthcare.

Health inequalities are also displayed by the use of technology among children of different ethnic minority and socioeconomic backgrounds. 20% of white children use continuous glucose monitoring to measure their blood glucose levels, compared to only 11% of black children. Furthermore, children living in socially deprived areas had lower uptake of technology, and experienced higher

average blood glucose levels than those in less deprived areas.¹

The changes to Integrated Care Systems could lead to increased variation in access to medical technology such as insulin pumps and glucose monitoring, given local ICS system leaders will have more power on what services are available within their defined geographic area. Areas with typically reduced uptake of technologies and innovative treatments must be empowered to embrace the changes announced in the bill and learn from best practice across the country, not fall behind.

The bill contains the General Function for Integrated Care Boards to have a duty to reduce inequalities between patients in access to health services and outcomes. This also includes an annual report explaining how the ICB has improved quality of services and reduced inequality. These measures are important, yet more must be done to understand why people from ethnic minority or lower socioeconomic backgrounds are not receiving equitable treatment for their type 1 diabetes as those from a white or higher socioeconomic background.

Medicines Registry and Data

The bill contains provisions for Medicine Information Systems, and expresses the potential value of comprehensive, UK-wide registries to improve patient safety and provide a rich evidence based analysis of medicines. The aim also is to link the prescribing data with data from clinical care, with additional bespoke patient-focused data. Data is extremely important when assessing treatments and medicines, so this will be an immensely beneficial tool going forwards.

JDRF is encouraging the government to go further with the establishment of registries and comprehensive data sources, in order to provide maximum benefit for people living with type 1 diabetes. Currently in England, there is no single, disease-specific registry for type 1 diabetes. By comparison, Scotland uses a register called SCI-Diabetes, where information recorded by technology can be uploaded in real time and evaluated by clinicians, better informing treatment options and improving health outcomes. It also informs research and can provide a more sound basis for clinical trials, thereby supporting the life sciences. The government must assess the benefits of introducing such a system UK-wide, and support more comprehensive data collection and sharing to support both service delivery and clinical research.

Innovation

The Covid pandemic has led to a new way of working, often at pace and increasingly reliant upon digital systems and software. Innovation of care was therefore a key element of delivering for people throughout turbulent periods. The White Paper, "Integration and Innovation: working together to improve health and social care for all", gave a large focus on the importance of innovation in

¹ National Paediatric Diabetes Audit, 2019/20

providing better health outcomes and delivering for patients.

However, within the Health and Care Bill the importance of innovation was largely limited to a General Function for Integrated Care Boards, who have a 'duty to promote innovation.' The government must go further to promote innovation within the NHS, and a drive towards more technology-based treatments. This would also support the Life Sciences Vision's precondition for success in making the NHS an Innovation Partner.

Type 1 diabetes provides a prime opportunity to be at the heart of innovation, given the advancements in medical technology treatments. This includes advances in insulin pumps, as well as Flash monitoring and continuous glucose monitoring. These developments allow a person more freedom with their self-management of their diabetes, and are supported through medical research funding from charities such as JDRF. People with type 1 diabetes who use these medical technologies may find it easier to manage their glucose levels and thereby reduce the risk of complications such as kidney disease, nerve damage, heart disease and premature death.

The future of diabetes treatment therefore involves further advancements in technology, for instance in the further development of artificial pancreas technology, where insulin is automatically administered based on readings from continuous glucose monitoring devices. A pilot of the artificial pancreas was recently announced by NHS England, providing a massive step forwards for people with type 1 diabetes, thanks to a commitment to innovation.

The government has a key role to play in bringing these technological innovations into development, and promoting widespread use, where anyone who would benefit from innovative and emerging technologies can access them on the NHS, thereby reducing health inequalities.

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