

JDRF Briefing: Health and Care Bill Second Reading

Introduction

This briefing has been prepared by JDRF in advance of the second reading of the Health and Care Bill.

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

Key asks

1. Ensure person-centred care is at the heart of the NHS, giving people with type 1 diabetes a greater voice and role in Integrated Care Systems
2. Address health inequalities, especially in access to technology amongst under-served groups
3. Embrace the value of data and introduce a central, UK-wide register for type 1 diabetes, modelled on SCI-Diabetes in Scotland
4. Empower the NHS to innovate and deliver technology-based treatments for type 1 diabetes

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. The government is proposing new legislation to reform the UK's Health and Care system, aiming to reduce bureaucracy, ensure accountability and deliver for people.

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

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.

Additionally, people must be able to make an informed choice regarding their access to diabetes

technology. This occurs firstly through having a number of different options available to them; with a wide range of treatment options available through the NHS. 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. JDRF's Pathway to Choice report of 2020 highlighted people with type 1 diabetes perceive healthcare professionals to often be time-limited.

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. The ordinary members of the ICB could also include a patient representative, or several. 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. Factors that can impede uptake include 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 Structures 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 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-focussed 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 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

¹ National Paediatric Diabetes Audit, 2019/20

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, 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 and through 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.

Our asks

1. Ensure and maximise person-centred care.

This involves bringing patient voice and experience formally into Integrated Care Boards and ensuring accountability of clinics and healthcare systems to local people. The government should also build towards delivering tailored and personalised care for people with type 1, where the priorities of the person with type 1 is factored into consultations and healthcare outcomes. This requires more time at appointments with clinicians.

2. Address health inequalities

There are a number of ways to address the disparities of access to treatment which exist across the UK. The government should ensure that clinics are offering the same treatments for patients, with consistent levels of training among healthcare providers so all are confident in prescribing new, emerging technologies. The government should ensure that those from lower socioeconomic backgrounds and those hardly reached receive the same level of care.

3. Embrace data to support health outcomes and research

The inclusion of medicines registries in the bill, along with wider government strategies promoting the use of data for clinical research and supporting patient reported outcomes is a strong step towards delivering for people with type 1 diabetes. The government must widen this initiative to create a single, UK-wide register of people with type 1 diabetes, modelled on SCI Diabetes in Scotland, allowing people to manage their own care and generate stronger research and development of new cures and treatments.

4. Invest in innovative technology

The Department for Health and Social Care should support research into innovative and technology-based treatments for type 1 diabetes. Moreover the NHS must uptake these treatments when they are available. This requires more enhanced training for healthcare providers so they feel confident in prescription. This is also facilitated through more comprehensive data collection and sharing, in order to better support clinical trials and garner more information into type 1 and its impacts

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