

JDRF Briefing: Health and Care Bill - House of Commons Remaining Stages

November 2021

This briefing has been prepared by JDRF in advance of the remaining stages of the Health and Care Bill in the House of Commons. 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. Protect the sustainability of the NHS through innovation and tech-based solutions
3. Address health inequalities, especially in access to technology amongst hardly-reached groups
4. Embrace the value of data and introduce a central, UK-wide register for type 1 diabetes, modelled on SCI-Diabetes in Scotland

Background

Around 400,000 people in the UK have type 1 diabetes, around 30,000 of whom are children. Whilst living with type 1 diabetes is typically defined by self-management, it is essential that people with the condition are able to access their healthcare teams for support in order to prevent such potentially life threatening events from occurring, as well as highlighting any related health issues that could arise from their type 1 diabetes, such as eye, feet or kidney problems. As the UK recovers from the Covid pandemic and routine healthcare appointments are reestablished, it is essential that the needs and priorities of people with type 1 are remembered within reform to the NHS in this Bill. As the NHS branches into the long-term use of telemedicine, it is important that people with type 1 are able to attend in-person appointments to address any potential complications arising from their type 1 diabetes; as part of a blended telemedicine approach.

Priorities: Person-Centred Care & Patient Choice

The introduction of Integrated Care Systems (ICS's) provides a number of opportunities to reform and improve type 1 diabetes care, leading towards a more integrated model. However it is essential that within the design of these new systems, people with type 1 diabetes are considered as partners rather than as participants and have greater influence in developing and defining the value of treatments that benefit them. This includes a role for patient representatives on Integrated Care Boards, including a representative for people with autoimmune or chronic conditions such as type 1 diabetes.

People with type 1 diabetes are often reliant upon their own behaviours and lifestyle in impacting their diabetes management, meaning each person with the condition is unique and will seek different outcomes. As such it is essential that both individual clinicians, as well as broader structures, have the capacity to personalise appointments to the needs of the specific patient. This requires investment from the NHS in both time and resources to free up capacity to hold in-depth discussions between parties and facilitate a one-size-does-not-fit-all approach to healthcare. It is therefore 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. Diabetes appointments predominantly involve assessing clinical outcomes such as a person's glucose levels record, determining if they have been consistently high, low or fluctuating between both. While this is important, in the future, it is crucial that the priorities of the person with type 1 diabetes, outside of their clinical checks, is also given stronger weighting. 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 preserves the right for patients to have a choice in their healthcare, for example in choosing a GP and GP Practice. This is crucial for people with type 1 diabetes, and must remain one of the central focuses of the Bill as it progresses. Many people with type 1 across the UK experience a postcode lottery when accessing treatment, meaning that they may be unable to access an insulin pump due to their local clinician's lack of knowledge of their use and benefit. Many clinicians also are unaware of the realistic nature of living with type 1 diabetes and the psychological toll it creates. People with type 1 diabetes are more likely to experience mental health problems than the general population, which must be urgently addressed within rebuilding of the NHS.¹

While ICS's have the intention to support localised approaches to care to meet population needs and reduce bureaucracy, it is key to ensure that postcode lotteries of care are not created through this by further entrenching the likelihood of regional disparities. Accountability and oversight mechanisms should include a summary rating for ICS's and would be underpinned by full data sharing across ICS's, so that regional disparities can more easily be identified and best practice can be observed.

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. Currently CCGs do not have a mandatory need to collect information on how many people with type 1 diabetes live in their area. This fundamentally weakens their ability to provide effective services that truly meet local needs. Given ICS's aim to be designed with a greater focus on local decision-making, this can be enhanced through more comprehensive data collection on patient demographics.

Innovation and Medical Technology

The Covid pandemic has led to a new way of working, often at pace and increasingly reliant upon

¹ JDRF, [Covid and Beyond: Confronting the unequal access to type 1 diabetes healthcare](#), 2021

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.

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. Access to technology has a number of benefits, both for the patient and for broader NHS sustainability. JDRF’s 2021 report “Covid and Beyond” also found evidence that people with type 1 diabetes who accessed technology were better able to self-manage their condition throughout periods of turbulence such as the pandemic.² Technology has also proven to improve blood glucose stability, therefore reducing potential future complications and hospitalisations from severe hypo- or hyperglycemic episodes.

Investing in technology, and the training required for its uptake is crucial to benefit the long-term sustainability of the NHS post-Covid. Whilst typically the NHS has given more weight to upfront or short-term cost-benefit, this has been detrimental in driving innovative new products and treatments into the hands of patients who could benefit from them. The ability technology gives patients to manage their condition without such a significant need for NHS intervention, as well as the longer term savings accrued through reduction in complications, means the government must empower the NHS to further accelerate access to life-saving technologies for type 1 diabetes and provide the funding and resources to do this.

Whilst the Covid pandemic has further strained the NHS, leaving reduced time for “non-essential” deemed functions, JDRF recommends that the NHS should provide protected time for training of healthcare providers on type 1 technology and its funding pathways. 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. This also provides the opportunity to reform methods of training for both clinicians and newly-diagnosed people with type 1, for example the introduction of virtual training courses or flexible timings for programmes.

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

Health inequalities

Many groups of people with type 1 diabetes experience health inequalities, and this is evidenced through National Diabetes Audits. Both adults and children from minority ethnic or socially deprived backgrounds are less likely to use technology to help manage their type 1 diabetes. For example,

² JDRF Covid and Beyond, 2021

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.³ This could lead to further disparity in health outcomes given the benefits that technology can provide, meaning all who could benefit from it should be able to access it if they choose.

As stated above, the changes to Integrated Care Systems could lead to increased variation in access to medical technology, 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 (ICBs) 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.

The unique needs and experiences of people from different cultural backgrounds and demographics also demonstrate the need to make services and structures more flexible. This includes accounting for different languages and literacy rates when carrying out appointments, understanding different people may benefit from virtual or face-to-face appointments. Structured education courses for type 1 diabetes should be provided in a number of languages as standard in the NHS, with greater outreach programmes to meet the needs of hardly reached groups.

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 specific register for type 1 diabetes. By comparison, Scotland introduced a system 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. The register should include a shared care record, accessed by patient and clinicians, to reduce time spent repeating health history with the different care

³ National Paediatric Diabetes Audit, 2019/20

teams supporting a person with type 1 diabetes.

It also informs research and can provide a more sound basis for clinical trials, thereby enhancing 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.

Key Asks

1. **Ensure person-centred service design.** This involves bringing patient voice into consultations when establishing new clinical structures, 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. This should also embed mental health support for people with type 1 diabetes within Integrated Care Systems.
2. **Invest in innovative technology to protect NHS sustainability.** The NHS should invest in treatments and technologies for type 1 diabetes that can accrue longer term cost savings through reduction hospitalisations and complications. The NHS must be supported to uptake these treatments when they are available, involving more enhanced technology training for clinicians to promote uptake and access.
3. **Address health inequalities.** 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. This should focus largely on people from lower socioeconomic backgrounds and those hardly reached. Access to technology amongst groups experiencing health inequalities should be monitored to prevent the gap widening. A focus on tailor-made services and personalised care will deliver healthcare that is more adaptive to the needs of each patient and reduce barriers of access.
4. **Embrace the value of real-world data.** The Bill should facilitate and encourage the collection of information on type 1 diabetes through introducing a national register, based on SCI-Diabetes in Scotland. This will enhance virtual appointments through data sharing on screen, and integrate care through providing a shared health record accessible to both the patient and their healthcare teams. It will also drive forward research and development of innovative new treatments and strengthen the real-world evidence base needed to demonstrate the value of emerging technologies and treatments for type 1 diabetes.

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