PRIORITISATION OF DIABETES FOR GOVERNMENT AND THE NHS

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APPG FOR DIABETES

About the All Party Parliamentary Group for Diabetes

The All-Party Parliamentary Group for Diabetes (APPG Diabetes) is a nonpartisan cross-party interest group of UK parliamentarians who have a shared interest in raising the profile of diabetes, its prevention and improving the quality of treatment and care of people living with diabetes.

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Key diabetes facts

- In the UK an estimated 4.6 million people across the UK are living with diabetes.
- An additional 1.1 million people are expected to have diabetes but undiagnosed, this is primarily Type-2 diabetes.
- Since 1996 the number of people diagnosed with diabetes has doubled, from 1.4 million to 3.8 million.
- Of those 4.5 million in the UK diagnosed with Diabetes it is expected that 10% have Type-1 diabetes and 90% have Type-2.
- When looking at genetic predisposition more than 85 per cent of Type 1 diabetes occurs in those with no previous first degree family history, the risk among first degree relatives is about 15 times higher than in the general population.
- The risk of a child developing diabetes if their mother has it is about 2–4 per cent higher than the average, if the father has it is 6–9 per cent higher and if both parents have the condition is up to 30 per cent higher than average.
- Type-2 diabetes can also be affected by genetics have a genetic pre-disposition. Those with diabetes in the family are 2-6 times more likely to develop the condition than those without history in the family.
- Diabetes is a condition which is expected to affect 1 in 10 people globally by 2040, equalling 642 million. This will put diabetes on a par with the number of people being diagnosed with cancer by 2040.
- Diabetes is a globally recognised condition. There is expected to be 1 in 2 adults across the world undiagnosed with Type-2 Diabetes. The International Diabetes Federation (IDF) has estimated that in 2015 seven countries have more than 10 million people with diabetes; China, India, USA, Russia, Indonesia, Mexico and Brazil.

Reports published by the APPG for Diabetes

- International Diabetes Summit (2019)
- Assessing the Diabetes Transformation Fund (2018)
- Flash Glucose Monitoring: what's next in Diabetes Technology (2018)
- Diabetes and Mental Health (2018)
- Reversing Type 2 Diabetes (2018)
- Diabetes and Podiatry (2018)
- Emotional and Psychological Support for people with Diabetes (2018)
- Next Steps for Childhood Obesity Plan (2018)
- The Future of Inpatient Diabetes Care (2017)
- Safety and Inclusion of Children with Medical Conditions at School (2017)
- Industry Action on Obesity and Type 2 Diabetes (2017)
- Levelling up: Tackling Variation in Diabetes Care (2016)
- Taking Control: Supporting People to Self-Manage their Diabetes (2015)

Prioritisation of diabetes for Government and the NHS

A session of the All-Party Parliamentary Group for Diabetes took place on the 28th February 2019 on Prioritisation of diabetes for Government and the NHS to discuss the next phase of the plan and the future challenges to diabetes and the health system that could threaten the delivery of the plan.

Key witnesses were;

- **Professor Jonathan Valabhji OBE** *and* **Dr Partha Kar,** *Diabetes and Obesity, NHS England*
- **Robin Hewings,** *Head of Policy, Knowledge and Insight, Diabetes UK*
- **Sarah Dunderdale,** *Diabetes Transformation Lead, and* **Carol Cottingham,** *Director of Service Re-design, Lincolnshire STP*
- **Andrea Beacham,** *Partnerships & GP Liaison Lead, Northern Devon Healthcare NHS Trust*

Professor Jonathan Valabhji OBE, *National Clinical Director, Obesity & Diabetes, NHS Trust*

"We managed to get almost all we wanted for diabetes in the NHS Long-term plan." – Professor Jonathan Valabhji

Professor Jonathan Valabhji spoke about the announced £20 billion increase of the NHS and the production of the NHS Long-term plan. He spoke about the NHS Diabetes Prevention programme and its role in assuring the sustainability of the NHS. He mentioned the high referral numbers and uptake of the programme, and how England became the first country in the world to offer this type of service, at this scale, for people at risk of Type 2 diabetes. Due to this achievement, NHS England announced in November 2018 that they will double the capacity of the NHS Diabetes Prevention Programme.

He talked about the Randomized Controlled Trial by Professor Roy Taylor for Type 2 remission which NHS England has trialled with 5000 people following a low calorie diet, for which NHS England will publish the results and see how best to move forward. He also spoke about the investments made through the Diabetes Transformation Fund and how the commitment has been continued on the NHS Long-term plan. "It is not only to improve care, but also understand how investments in care can lead to savings in the long-term. This is a new and important way to think about care".

He explained how the burden of diabetes sits within complications. "If there are improvements in the achievement of treatment targets, access to diabetes education and access to specialists in foot care and diabetes hospital care, you can see the reduction in complications". He explained how funding for a second phase of diabetes Transofrmation Funding has been guaranteed in the NHS long term plan to prevent a 'fall face'. "There will

be tampering down, because that was the deal. But for areas like education, where it takes much longer to see results, there will be tampering down over the next 10 years".

Dr Partha Kar, *Consultant in Diabetes & Endocrinology, Portsmouth Hospitals NHS Trust*

> ***"We cannot fund everyone for Flash, but we have made a big commitment that hopefully is appreciated." – Dr Partha Kar***

Dr Partha Kar spoke about NHS England's priorities regarding Type 1 diabetes and their focus on improving patient care. He explained some of the resources developed for people with Type 1 diabetes, including Language Matters and the Diabetes Technology Pathway. He highlighted the commitment NHS England made in regards to Flash Glucose Monitoring which will be centrally funded from April 2019.

He mentioned the economic work conducted by Helen Murphy as a example of how research should influence policy; the recent NHS Diabulimia announcement; the NHS Apps Library; and the Mental health work conducted with Diabetes UK. He spoke about Getting It Right The First Time programme where NHS England is going to hospitals and sharing good practice. "It is not just about technology, we need the workforce in place to deliver it. There is a lot of things happening. Lots of things moving".

Robin Hewings, Head of Policy, Knowledge and Insight, Diabetes UK

> ***"We are not going to get consistently good inpatient diabetes care without skilled and motivated staff to actually deliver it." – Robin Hewings***

Robin Hewings said the prioritisation of diabetes has grown incredibly. The growth of the Diabetes Prevention Programme, the Diabetes Transformation Fund, and now the very comprehensive commitments in NHS England's Long-term Plan are exciting.

Robin explained how in terms of what Diabetes UK wanted to get in the NHS Long-term plan, almost everything was there. "Taken together these changes have the potential to make a real difference. But turning the plan into reality will not be easy". He explained how what was not in the plan relates to the wider system; the external environment which can present a big challenge to the commitments made to diabetes.

"The NHS is still under real strain. It is just one part of the health system alongside public health and social care. A reversal of cuts to public health, resources to get the NHS staff we need, and a way of paying for proper social care are all needed if we are to have a sustainable health system. The very welcome commitments in diabetes will only come about if there is a healthy NHS to deliver them".

Sarah Dunderdale, Diabetes Transformation Lead, Lincolnshire STP and Carol Cottingham, Director of Service Re-design, Lincolnshire STP

> ***"The funding streams enabled county wide focus, which highlighted the sheer scale of the issues. Diabetes is now a key priority for the STP." – Sarah Dunderdale***

Sarah Dunderdale talked about Lincolnshire being a large rural county with significant areas of deprivation, obesity and high prevalence of Type 2 diabetes in the country at 14.4% on the East Coast. At Lincolnshire they are determined to tackle the issues that are preventing those with diabetes in the county from living long healthy lives. This will be done by integrating services and ensuring clinicians and patients have knowledge and confidence to manage the condition well, wherever they live in the county. The NHS England Treatment and Care funding enabled the STP to focus on diabetes; the work done ensured that diabetes became a system wide priority supported by all CCGs and providers. The NHS Long Term plan further supported the programme via its ambitions for: prevention, integration, technology, mental health access, weight management services, self-management, shared care and infrastructure such as Primary Care Networks.

Sarah mentions how relationship building has been key in navigating the inpatient care network, integrated health systems and infrastructure changes. "It is key to have the clinicians on board. Having people pick up the phone and have those conversations". But she highlights that these relationships take time, despite all the NHS support to help sent them on the path they needed.

Lincolnshire has made diabetes a priority for the local NHS and government and believes the changes will make a significant difference to patients and they hope others will do too.

Andrea Beacham, Partnerships & GP Liaison Lead, Northern Devon Healthcare NHS Trust

> ***"The best way to support people with diabetes to manage their health well is to create a framework where understanding is the catalyst for actions."– Andrea Beacham***

Andrea Beacham said that North Devon has seen a significant reduction in diabetes related harm after co-designing integrated care with people with diabetes since January 2017. The partnership model is based on the premise that the best way to support people is to create a framework where understanding is the catalyst for change.

After listening to what matters to people with diabetes, the team identified how to deliver what was needed in partnership across the care pathway. She explained the projects put in place 'STOP, LOOK, LISTEN, TEST AND RESPOND', as well as their limitations, outcomes and

further recommendations. Recognising that the majority of people are supported in primary care, specialists in diabetes and foot care now spend time out of hospital providing education and support in GP practices and community wellbeing events. Personalised care-planning, underpinned by motivational interviewing has been built into diabetes reviews and a link nurse programme delivers improved quality of care for housebound patients.

Despite prevalence of diabetes in North Devon increasing from 7.1% to 7.5% since starting the project, emergency admission to hospital for people with diabetes has reduced from 16% to 13%. Average length of stay has reduced and, despite an over 50% increase in referrals to podiatry, average waits have reduced by 10%.

North Devon has been a pioneer in building community systems infrastructure with statutory and voluntary partners addressing wider determinants of health and wellbeing. If there is to be a shift towards population health, community wellbeing partnerships need to be given the same emphasis as STP level partnerships. To tackle heath inequalities, local teams need flexibility to spend more time with people most in need of support to understand the person in context.

Audience discussions:

Keith Vaz MP mentioned the need for a larger prioritisation of education for people with diabetes. "I think it has gone wrong in England. We have given a lot of money to companies who are not doing what they are supposed to be doing in the field. I am shocked to see the amateurish service being offered by companies receiving a lot of money from the NHS", he says. *Nigel Gainer* agreed with the Chairman and, after sharing his own challenge accessing diabetes education, asked NHS England why Dafne courses were not offered across England. *Dr Kar* responded by mentioning how there are often patients who do not attend Dafne courses, despite being offered them. He explained how the reality is that a lot of people cannot even attend, due to not obtaining time off work. He highlights the importance of giving people with diabetes options.

Keith Vaz MP also highlighted the issue with data and how information might not be 'held centrally', a response he received to many written parliamentary questions (WPQ) raised. "It is important to continue to ask these questions to continue to pressure government and show that we are watching". *Lord Brooke of Alverthorpe* agreed with the Chairman and shared his experience of failing to obtain answers, highlighting the disaggregation of data due to funding cuts. *Professor Valabhji* responded to these questions by mentioning the Health and Social Care Act, and how when something is commissioned locally, the data remains locally. He notes, however, the diabetes data NHS England has is better than anywhere in the world. He also explains the issues with delay in obtaining data and how, as the NHS will start to report quarterly, their capacity to respond to WPQs will improve. Finally, he clarifies how there are things NHS England cannot realistically ask clinicians to respond. "Our response rate with GPs is 15%"

Dan Parker asks what kind of support the 5,000 people going through the low calorie trial will receive to get back to eat normally. David Cavan asked whether NHS England is aware of data in the US presenting evidence for low carbohydrate diet and Type 2 diabetes remission.

Professor Valabhji responded by explaining the importance of Randomised Controlled Trials (RCTs) and its difference to anecdotal evidence. He also highlights an increase in interest for lifestyle change interventions, mentioning the NHS Diabetes Prevention Programme and the importance of addressing social-economic components that impact any dietary intervention. "That is our main challenge". Finally, he answered that NHS England has met with the aforementioned US Company and seen their data, explaining that a randomized controlled trial (RCT) had not been conducted and there were concerns over the increased levels of LDL cholesterol. "It may work, it may not, we just do not know. There is not yet enough data."

Maggie Meer asked NHS England what service model they were going to use to ensure all pregnant women with Type 1 diabetes will have access to CGMs, as promised on the NHS Long-term Plan. *Dr Kar* responded by informing NHS England has built a working group to plan how the service will work.

Keith Vaz MP asked NHS England what are their five priorities on diabetes and why, in terms of prioritisation, diabetes has not reached the stage of cancer. *Professor Valabhji* answered the priorities are Type 2 prevention (highlighting T1 prevention is currently being researched), structured education, achievement of treatment targets, preventing amputations and inpatient care. *Dr Kar* responded that, if all datasets are compared, England does better on diabetes than on cancer and cardiovascular diseases. "The issue is that there is a media rhetoric around cancer that is different to diabetes. We need to shift the narrative. Patient voice has a lot of power and we need to see more of it. 123"

Recommendations:

- Ensure there is a dedicated post for diabetes in each sustainability and transformation plan (STP) to ensure prioritisation of diabetes within the NHS and local government.
- Future funding programmes should consider integration projects which enable long term sustained transformational change rather than short term specific goals.
- Identification of synergies across funding streams e.g. Mental Health Improving Access to Psychological Therapies (IAPT) and diabetes.
- There is a need to be mindful when scaling up the NHS Diabetes Prevention Programme, and be more conscious of the groups at risk we need to reach.
- If there is to be a shift towards population health, community wellbeing partnerships need to be given the same emphasis as sustainability and transformation plan (STP) level partnerships.
- To tackle heath inequalities, local teams need flexibility to spend more time with people most in need of support to understand the person in context. Take the time to understand the issues from the perspective of everyone involved by understanding what is really needed, working out how to do what's needed with the people who will be doing it and making the links that help join up the pathway to provide a system solution.