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Bringing medicines to *life*

A diabetes snapshot

A report from the ABPI Pharmaceutical Diabetes Initiative

24,000

people die from avoidable diabetes complications each year

The total annual cost of treating diabetes complications is

£7.7 billion

versus treatment costs of only £2.1 billion

Diabetes UK, *Cost of Diabetes*, 2014[1]

There has been a huge increase in largely avoidable complications since 2006

Cardiac failure has increased by

104%

Strokes have increased by

87%

Kidney failure has increased by

77%

Every year there are

1,280

new cases of blindness caused by diabetic retinopathy

The incidence of children with diabetes being admitted with diabetic ketoacidosis – a potentially life-threatening complication that can lead to death if untreated –

has almost doubled since 2005

Over **100 amputations**

are carried out every week due to complications; 80% of these are avoidable

Diabetes UK, *State of the Nation*, 2013[2]

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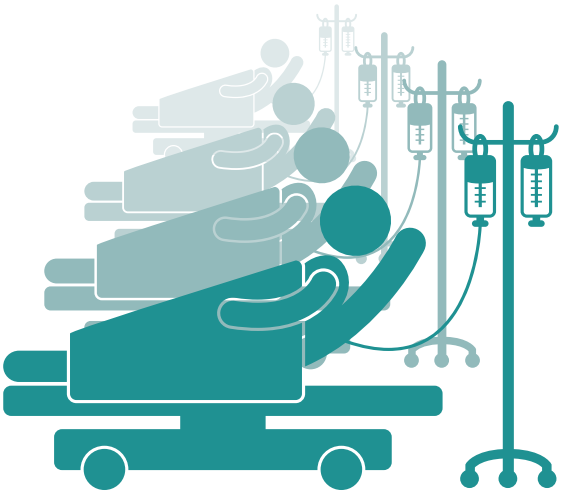

The percentage of beds in acute hospitals occupied by people with diabetes increased to

15.8%,

up from 15.3% in 2012

Inpatients with diabetes admitted to hospital as an emergency

had a longer median length of stay

in hospital (eight nights) than inpatients with diabetes admitted electively (six nights)

Diabetes inpatient specialist nurse (DISN) availability has still not improved

– almost 1/3 of hospital trusts still have no DISN

71.2%

of hospitals had no specialist inpatient dietetic staff time for people with diabetes

National Diabetes Inpatient Audit, 2013[3]

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The quotes expressed in this report represent the views of the research participants, and not necessarily those of the ABPI PDI or any individual member company.

This research has been fully funded and commissioned by the members of the Association of the British Pharmaceutical Industry Pharmaceutical Diabetes Initiative (ABPI PDI). Members of the group include Abbott, AstraZeneca, Boehringer Ingelheim, Janssen, Lilly, MSD, Novo Nordisk and Sanofi.

The stakeholder interviews were conducted by a third party (ComRes). The ABPI PDI proposed the areas to be covered in the interviews.

The intended audiences for this report are policy-makers; officials within NHS England and the Department of Health; and healthcare professionals. This document includes a summary of findings with a series of quotes from respondents in support of those findings. A more detailed summary of responses and analysis is available on request.

People with diabetes who are currently on medication should consult with their healthcare professional as they would normally do when discussing the management of their diabetes.

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Foreword

Dr David Miller-Jones
Chair, Primary Care
Diabetes Society

The steep rise in diabetes cases in recent years has been overwhelming for those charged with planning healthcare services and especially in primary care. But, more than this, each individual case is a potential personal tragedy of pain, stunted quality of life and for some, untimely death.

This collection of views from the front line of diabetes care is a welcome reminder of the challenge facing the NHS in managing this epidemic. We know that diabetes is manageable, but that it is never consistent and every individual experiences it in different ways. To help people get the best possible quality of life means offering a high level of tailored support and treatment – something difficult to achieve at scale. While there has been undeniable progress over the past decade, major variation and gaps in support for clinicians still exist.

General Practice is now carrying more responsibility for managing this complicated condition than ever before. This is not just in the consulting room, but also in the design and commissioning of local systems. Many GPs report feeling overwhelmed and under-supported. Resources to meet this challenge are spread thinly and there is conflicting advice on priorities.

The Primary Care Diabetes Society is doing much to provide education and national leadership, but our aims of supporting GPs would be strengthened by a renewed national NHS policy commitment to tackle diabetes. The recent NHS England action plan has the right ambitions – this snapshot demonstrates that it now needs to be followed by detail.

PCDS
Primary Care Diabetes Society

Suzie Collett
Chair, ABPI PDI

Rachel Cummings
Vice Chair, ABPI PDI

Diabetes is one of the most difficult health challenges of our times. The ABPI Pharmaceutical Diabetes Initiative (PDI) is a collaboration of the main pharmaceutical companies developing and manufacturing diabetes medicines and devices with the aim of supporting optimal treatment for people with diabetes.

There has been considerable innovation in diabetes medicines and devices in recent years which have offered a greater range of options to personalise treatments, reduce side effects and improve the lifestyle for people living with the condition. We believe modern medicines are part of the solution to manage and reduce the personal and financial costs of poorly controlled diabetes, and that more could be done to help people living with diabetes to get the most out of their medicines.

There is more that can and should be done to create consistently excellent healthcare services for diabetes care in the UK. This collection of voices from commentators, policy-makers and clinicians offers a snapshot of where the UK is on managing diabetes. It offers some useful viewpoints on how this could be achieved, from bolstering clinical education and finding new ways to involve and motivate individuals in their own care, to ensuring that rational and achievable incentives are in place across the healthcare system. The ABPI PDI will be using this research to inform its future strategy to drive progress in managing diabetes.

We would like to offer our thanks to Dr David Miller-Jones, Chair of the Primary Care Diabetes Society, for his support on this project, and to all our members for their contribution.

Above all, we would like to thank all those who participated in our research. They represent the many who are working hard on the front line of the NHS, caring for and treating all those living with diabetes.

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1. About this project

In March 2014, the ABPI PDI commissioned independent research consultancy ComRes to conduct an extensive research project to gather insights into challenges in current policy and practice, and the future of diabetes care in England.

This research is based on 50 in-depth interviews with a cross-section of people working in diabetes: from those setting and shaping policy in Westminster to those commissioning, delivering and representing those who receive care on the ground.

The aim of this project has been to:

- engage directly with the diabetes community, including decision-makers, patient groups and front-line staff to understand the challenges facing them in the NHS landscape
- showcase the principles of good diabetes care and identify the changes needed to enable patient access to treatment that delivers the best outcome for them
- demonstrate ways in which the new NHS – in partnership with industry and others – could work better for people with diabetes, making best use of extensive existing tools, resource and guidance
- define what success looks like for people living with diabetes, and in doing so encourage progress towards a consensus on good clinical management in diabetes
- share our learnings with NHS England, the Department of Health and the wider diabetes community.

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2. Our approach

The research

ComRes interviewed 50 senior opinion formers and healthcare professionals in diabetes care between July 2014 and October 2014. Interviews lasted between 20 and 40 minutes and were conducted personally by ComRes consultants.

In order to carry out this work, ComRes designed a research project to explore the perceptions of senior opinion-formers on diabetes care on the following issues:

- performance in diabetes care at both a local and a national level
- issues and challenges currently facing diabetes services, and how these could be overcome
- the current balance between prevention and treatment, and whether this is perceived to be correct
- the impact of recent NHS reforms on patient care for people with diabetes
- the effectiveness of current and past policy levers, including financial incentives, clinical guidance and top-level policy objectives
- their definition of 'success' under the current policy regime, and whether this tallies with their own perceptions of what success looks like in diabetes care
- the value attributed to medicines and health technologies as part of the solution, and the view on where new medicines and technologies fit into that
- drivers of real change in clinical practice, and whether this is driven on an individual, local or national level
- recommendations for how the state of diabetes care in the UK can be improved, and insights into what changes need to be made in order for these to be implemented.

Stakeholder engagement

Following the completion of the research, the core findings were presented to a group of primary care stakeholders at the Royal College of GPs. The meeting, hosted by the ABPI PDI and facilitated by Dr David Miller-Jones (Chair, Primary Care Diabetes Society), engaged primary care leaders both with a diabetes specialism and a more generalist focus. ComRes presented the findings to the group of 14 stakeholders; this was then followed by a discussion. Outputs from this meeting are included throughout this report.

3. Why now is the time to get diabetes right: the ABPI PDI's vision for 2015

Every three minutes someone in the UK is diagnosed with diabetes. This means that by 2025 five million people will be living with the condition.

To underestimate diabetes would be a mistake. When poorly managed it is the cause of 24,000 early deaths (2011).[4] If ignored, type 1 and type 2 diabetes will cost society £39.8 billion by 2035 (2013).[5] To date the prevention of diabetes has been considered a leading priority. Government has made significant investment in national education campaigns and the promotion of healthy living; a message which is important in the fight against obesity and tackling rates of type 2 diabetes.

However, it must not be the sum of our efforts. We cannot forget those living with diabetes now and those who are at risk of developing potentially devastating complications if their condition is not well managed.

We believe that, no matter how complex a person's condition might be or where in the country they live, it is possible to live well with diabetes. The challenge is the consistent and timely application of what we know to be good clinical practice.

That is why now is the time to get diabetes right, for the benefit of people living with diabetes now and in the future.

A diabetes snapshot reinforces the view that, despite national guidance, innovative treatments and technologies being widely available, people being diagnosed with diabetes in 2015 may not receive optimal care and treatment pathways, despite living longer.

The research also shows us that the system is not working as it should for patients. When ComRes approached NHS England's Local Area Teams for their views on the commissioning of diabetes and long-term condition services, the teams expressed little knowledge of how these services are being managed in their patch, and felt that it did not fall within their professional remit. This naturally raises some concerns, particularly as these are the organisations tasked with commissioning primary care services within a region.

In order to make a difference, the ABPI PDI is calling for the implementation of the optimal treatment pathway. We know that, when implemented early, the right treatment can have a positive impact, not only on the patient, but also the taxpayer – keeping people healthy, at home, in work and out of hospital.

To achieve this, we want to work with partners to ensure that those on the front line of primary care have the knowledge and confidence to prescribe the best available medicines and technologies for the right patient, at the right time.

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PATIENT
DATE
DOSAGE
TREATMENT
SKIN ERUPTION SYMPTOMS

4. What did people tell us?

Interviews were conducted by a third party (ComRes). The quotes expressed in this report represent the views of the research participants, and not necessarily those of the ABPI PDI or any individual member company. The intended audience for this report is policy-makers, NHS England and Department of Health officials, and healthcare professionals. People with diabetes currently on medication should consult with their healthcare professional as usual when discussing the management of their diabetes.

Key: colour-coded text

- Purple – Research findings: these are the key ComRes research findings, inclusive of quotes sourced directly from research participants who have given permission for their responses to be shared anonymously
- Blue – The GP view: these are the views of GPs (both generalist and specialist) who were consulted on the findings of the initial research
- Green – The ABPI PDI view: these are the views of the ABPI PDI based on the research findings and other available data and statistics

Key: symbols


Academic


Diabetes specialist nurse


Diabetes UK


Diabetologist /GP with a Special Interest (GPwSI)


Journalist


NHS manager


Parliamentarian


Patient group


Policy official


Professional body

The following sections of this chapter reflect the areas covered by the interviews:

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Below we outline the core themes that emerged from the research conversations.

Diabetes as a national health priority

Diabetes is no longer considered a national health priority: Diabetes has reportedly slipped down the list of national policy priorities in recent years – with the loss of NHS Diabetes, the previous national standards body for diabetes, seen as a key determining factor.

"I think you can point to some of the programmes NHS Diabetes was involved in, like foot care and inpatient diabetes, and I think it is much harder to maintain that focus after NHS Diabetes was dissolved." **(Diabetologist)**

"Looking at the way the present system is working, I feel that [diabetes] is a little bit ignored." **(Parliamentarian)**

The GP view

Diabetes is still considered a priority by those on the front line of primary care. The challenge is the expectation that they become long-term condition specialists, no longer managing a single condition, but multiple complex co-morbidities.

"... 70 per cent of GP workload must be now supporting people with long-term conditions ... and actually the NHS is not designed for that. It's been designed for acute models of care, where things get fixed and people go home ..."

Cancer, obesity and dementia attract more political attention: Cancer and dementia are considered personal priorities of the political leadership, with diabetes seen only as 'part of' obesity and therefore predominantly a public health issue.

"In comparison with other disease areas, we do probably talk more about cancer as a specific disease area. There is also a lot of focus on dementia." **(Policy official)**

"You only have to see it in recent days with Cameron's response to access to early diagnosis in relation to cancer, and access to treatment and so on. One doesn't get a sense of those sort of headlines for diabetes." **(Diabetes specialist nurse)**

Type 1 diabetes is being unduly overlooked in favour of type 2 diabetes: Concerns were raised that treatment and care for types 1 and 2 diabetes are being poorly differentiated, in part driven by an increased societal focus on obesity and lifestyle-related conditions.

"I think type 1 diabetes is significantly undermined by the huge number of people that have type 2 diabetes." **(Diabetologist)**

"The two diseases [type 1 and type 2] are very different and I'm not convinced the government really understand what they should do or how they should respond." **(Academic)**

The complexity of diabetes is poorly understood: The complexity of managing diabetes is now reported to be less well understood by policy-makers and is leading to simplistic policy-making which undermines the treatment of diabetes as an acute condition.

"Primarily, I feel diabetes is a socio-economic problem. It is to do with lifestyle, level of poverty and deprivation, the street you live in, etc." **(NHS manager – commissioner)**

The tools are available to help people live well with diabetes, but we're still not getting it right.

Innovative treatments and technologies are available; high-quality national guidance is in place; and there is an extensive evidence base. Policy frameworks are in place, and the tools to measure and incentivise success are well established.

The delivery structures are in place to help people with diabetes live well; why then do outcomes remain poor?

- Diabetes as a long-term condition is acknowledged within Domain 1 of the NHS Outcomes Framework, the Public Health Outcomes Framework, the Cardiovascular Outcomes Framework and the CCG Outcomes Indicator Set. In early 2014, NHS England published the Action for Diabetes Plan, setting out what it intends to do for those living with, and at risk of diabetes.
- Domain 1, "preventing people from dying prematurely", and Domain 2, "enhancing the quality of life for people with long-term conditions", are in place to hold NHS England to account for its performance in these critical areas.
- National clinical guidance is also in place to support the delivery of consistent quality care in diabetes. Both NICE Clinical Guidelines for type 1 (CG15) and type 2 (CG87) are currently being updated, with a further two new sets of Guidelines in development – for children and young people and diabetes in pregnancy. The NICE Quality Standard for Diabetes in Adults has also been in place since 2011.
- In 2012, NHS England and the Royal Pharmaceutical Society published a set of principles to support healthcare professionals and patients to get the best possible outcomes from medicines. NHS England has since published a prototype Medicines Optimisation Dashboard, which is designed to collate a range of data to help CCGs understand how well their local populations are being supported, to optimise medicine use and inform local planning.
- Not only is there guidance on what 'good' looks like for people with diabetes, mechanisms are also in place to support and incentivise delivery. The Quality and Outcomes Framework (QOF), the Commissioning for Quality and Innovation payment framework (CQUIN) and Best Practice Tariffs (BPT) are all in place to encourage excellence in care delivery and outcomes.
- Diabetes is well supported by an active and expert patient advocacy community. Diabetes UK and the Juvenile Diabetes Research Foundation (JDRF) are among those publicly campaigning on behalf of people living with diabetes, keeping the issue on the public and political agenda.

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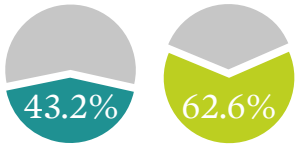
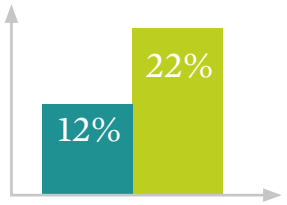
Type 1 vs type 2: a picture of mixed success

In early 2014, NHS England acknowledged areas for improvement in diabetes care, in particular highlighting the disparity in care available for those with type 1 diabetes compared to type 2. For example, completion rates of the recommended care processes are lower, and the achievement of NICE-recommended glucose targets are markedly worse for those with type 1 diabetes.[6]

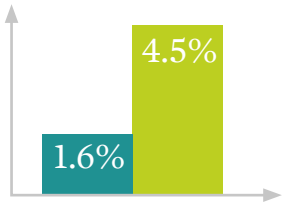
Disparity in care: type 1 vs type 2



Only **43.2% of those with type 1 diabetes** and **62.6% of those with type 2 diabetes** received all nine of the care processes.



Only **12% of people with type 1 diabetes** and **22% of people with type 2 diabetes** met their blood pressure, cholesterol and HbA1c targets.



Only **1.6% of type 1 patients**, and **4.5% of type 2 patients** are offered structured education about how to manage their condition.

Type 1 diabetes **Type 2 diabetes**

National Diabetes Audit (2012)

The state of diabetes care

Widespread variation in care and outcomes: Respondents felt that there is no consistent picture of diabetes care in the UK. Wide variation is said to be the main feature of diabetes care and is seen as the central obstacle to overcome.

"The best practices do twice as well as the poorly performing practices. We've got too much variation. We need to improve the quality of the bottom 25% to get them up to the average." **(Diabetologist)**

"I think, like many other areas, it [diabetes care] is very effective in some places and less so in others. There are still really significant differences between different health areas [...] in terms of what access they have to specialist care and the sort of education programmes they are providing for people who are diagnosed with diabetes. It is very inconsistent across the UK." **(Professional body)**

Evidence of both the exemplary and the unacceptable: Some areas are said to provide truly excellent diabetes care, exemplified by strong clinical partnerships, active local champions and knowledgeable doctors and nurses in primary care. However, stakeholders also point to many areas which provide unacceptably low quality care and produce poor patient outcomes.

"I think it depends on who's leading it in different areas. If there is a particular diabetes lead, or a real champion for diabetes care, then I think the care is pretty good." **(Diabetes specialist nurse)**

"I think you see the discrepancy in hospital care [...] in some areas, when diabetic patients get admitted in an emergency, they go in under the general admitting teams, not the specialists. And, as a result, most people who are admitted into hospital with diabetes are looked after by non-specialists and the level of care is truly terrible." **(Academic)**

National and local leadership vacuum: Diabetes specialists highlight the break-up of NHS Diabetes and the devolution of power to local Clinical Commissioning Groups (CCGs) as major contributing factors to ongoing variation in diabetes care and outcomes.

"This [regional variation] is an inevitable consequence of the shutdown of NHS Diabetes and lack of national drive. Decisions are now made at the regional level by the CCGs. If they do not consider it a priority then it becomes very difficult. It depends what they see as a priority and it may or may not include diabetes." **(Diabetes specialist nurse)**

"Some people get good care but it's entirely geographically patchy and mostly determined by the level of clinical leadership at a local level." **(Patient group)**

The GP view

National leadership was recognised, but GPs felt that this leadership lacked the necessary support structures and resource to make a real impact on the ground.

"... we have a national clinical director ... he doesn't have the resources. He leads to the best of his ability but doesn't have an infrastructure around him ..."

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Lack of clinical skill and interest: The varying level of diabetes knowledge and expertise amongst GPs and practice nurses is seen as a fundamental problem. Participants expressed fears that there are GPs who are either not competent or not confident enough to treat diabetes or educate their patients with diabetes to a sufficiently high level.

"Sometimes healthcare professionals [HCPs] don't address the problem because they don't know what to do about it. I think it is about educating them to meet that patient's needs, because sometimes things are not discussed or changed, because the HCP is not sufficiently confident or competent, or does not have enough skills or knowledge to take that forward." **(Diabetes specialist nurse)**

"There are GPs who are just not interested in diabetes. In my clinic, I ask 'When did you last get your urine checked?' and they say 'I don't get it checked'. Even though QOF pays for it, they aren't interested or can't be bothered so they take the financial hit." **(Patient group)**

The GP view

The GPs we spoke to report an acute lack of time and resource to manage people with diabetes. It is not a lack of skill or interest, but the constant pressure to *"fire fight"*. When asked how GPs do manage the growing diabetes case load, the answer was *"we muddle through"*.

The fact remains that outcomes for people with diabetes are not good enough and 80 per cent of NHS spending on diabetes goes into managing *avoidable* complications.

Diabetes is responsible for up to 100 amputations every week, 80 per cent of which are avoidable (2013);[7] it remains one of the leading causes of blindness in people of working age (2014);[8] and results in 600,000 excess hospital bed days (2013).[9]

In Diabetes UK's most recent *State of the Nation* report, Chief Executive Baroness Barbara Young noted that, in spite of the growing number of people experiencing these devastating complications, *"the NHS still struggled to deliver the care and education [they] needed to manage their condition"* (2013).[10] This analysis of the NHS' performance in diabetes demonstrated little improvement in recorded outcomes – indeed, in some areas it highlighted a marked decline.

Poor outcomes in diabetes have attracted the attention of both the National Audit Office and the Public Accounts Committee in recent years, with the 2012 NAO report stating quite clearly that the Department of Health had *"failed to deliver diabetes care to the standard it set out as long ago as 2001"* (2012).[11] While NHS England rightly acknowledges progress made – including marked reductions in excess mortality, and the lowest rates of early death due to diabetes – there is still the opportunity to do more (2014).[12]

Regional variation

The most recent National Diabetes Audit found that rates of access to the nine NICE-recommended care processes varied considerably depending on where people lived. In the best performing areas people with diabetes were four times more likely to get the checks they needed, compared to people living in the poorest performing areas.[13] Although the Audit showed that rates have improved, 36 Primary Care Trust (PCT) areas in England recorded fewer than half of their patients as having had all their annual GP checks.[14]

Medicines and technologies

Strong innovation in pharmacology: Stakeholders recognise that there is a broad range of treatments and technologies available to treat diabetes in the best possible way.

"There have been some effective medicines in the past five to ten years. I think generally prescribed medicines are also very effective. There's no doubt that GLP-1s and DPP-4s have both had quite a significant impact upon care." **(GPwSI)**

Knowledge to support optimal prescribing is lacking: Barriers to the use of new medicines are said to include a lack of knowledge and confidence amongst primary care professionals on how to build these new medicines into a patient's treatment plan.

"I think that for the newer stuff, specialists tend to be a bit more in the loop, while non-specialists looking after patients might not be as up on the new stuff as the specialist is." **(Diabetologist)**

"There was a very clear pathway at one time – metformin, sulfonylureas and insulin. Now there are so many medications and they can be used in different combinations. More skill is required to know what will suit each person." **(Diabetes specialist nurse)**

The GP view

The GP group noted that non-diabetes specialists are not always aware of newer agents or technologies and often lack the confidence to push back against prescribing barriers.

"... often people know about these agents but rarely use them and lack the confidence to actually do it ... it depends on how brave you are and how good your CCG is ..."

Local prescribing guidelines limiting clinical freedoms: Respondents, including healthcare professionals, were critical of the cost-cutting imperative which is forcing CCGs to recommend the cheapest available medicine over the most clinically effective. This is leaving GPs with little freedom to prescribe as they consider clinically appropriate.

"Even if there are better medicines available sometimes, people are not prescribed them because of cost implications." **(Professional body)**

"I think it's a difficult time for medicines and technology because we are driven by the CCGs and their price restrictions on a lot of medicines." **(Diabetes specialist nurse)**

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Short-term view of CCGs impacting on outcomes: CCGs are reportedly driving prescribing behaviours that deliver short-term cost savings, but that have the potential to deliver poor patient outcomes in the long term. In the absence of a local clinical champion, this pattern of behaviour is said to be becoming the norm.

"I personally was hauled up by my prescribing adviser and was told I was haemorrhaging money in my treatment of diabetes, and other people were dying so my patients could get expensive drugs. It was horrible, they were so ignorant. So I did an audit and eventually persuaded them that I was very cost-effective in prescribing for diabetes. All these GPs who aren't interested in diabetes will use sulfonylureas because it will keep them out of trouble, because they are cheap. But they are not cheap if you have a hypo, fall down the stairs and break your hip. Not everyone would put up a fight like I did." **(GPwSI)**

"As a CCG we are looking at whole pathways of care and not just the individual cost of drugs. So it's pumping in the right drug which may be very costly earlier on in the disease but its trajectory gives you a longer life, better output from the patient and less expense at the tail-end. In macro-healthcare we're not sophisticated enough to see it in that way, but we are working towards it." **(NHS manager – commissioner)**

Early intervention can deliver results and mitigate clinical risk in the long term: Investment in the right medicine, early in the patient's pathway, is considered to be more cost-effective in the long term.

"Open studies like UK PDS show that you only treat diabetes successfully if you do it early, and if you do it early you produce legacy effects." **(Patient group)**

"Clinicians like to think quite long term. We can't close things down within the financial year, yet the people who are commissioning and making decisions from the point of view of resources tend to be people looking for short-term gains. Diabetes, as an example, is not like that. It's very much a long-term condition and it's something which you can tackle over months and years, not days or weeks." **(GPwSI)**

Technology has the potential to deliver, but uptake is poor: The use of insulin pumps, continuous glucose monitors, telehealth, smartphones and apps can dramatically improve the lives of people living with diabetes. However, adoption in the NHS needs to be improved, with patients able to access more sophisticated devices that are fully integrated into the NHS.

"I think they are not being used as effectively as they could be. If we talk about technology first, again it goes back to educating the patient, and the professionals to some extent, about how to look after their diabetes through remote monitoring so that you can do your bloods regularly, you can keep a record, it can automatically be sent through and received at a GP surgery or by a practice nurse. So you need that sort of technology to help people to look after their diabetes better." **(Professional body)**

"I do think there are technologies that are out there, like apps to monitor calories or blood glucose and to monitor it and download it, that kind of technology. If they could be integrated, it will be very useful. We do have technologies, but it's about how you build them in so the patient isn't just doing it on their own and instead they become part of the working relationship." **(Diabetes specialist nurse)**

Diabetes is not clear-cut – it can be straightforward, it can be complex – but it is almost always manageable.

Organising care

Organising care for diabetes can be complex, now more than ever. Major reform of the health service has led to a new way of purchasing, designing and delivering diabetes care services. A new generation of commissioners is grappling with a large and ever-growing patient population, who need support from a wide spectrum of providers, from GP practices and community clinics to emergency departments and specialist centres.

Not only has the landscape changed, but the patient population itself has become increasingly varied in its complexity. More people are living with diabetes; they are living for longer; and often with more than one additional condition. The Department of Health estimates that the number of people living with multiple comorbidities will increase from 1.9 million in 2008 to 2.9 million in 2018 (2014).[15] Some of these patients will stay well and in control of their symptoms. Others are likely to present as highly complex cases, thereby placing significant pressure on the NHS, in terms of both resource and expertise.

As a result of this growing and diverse patient demand, coupled with a fluid landscape, care can be fragmented, with people seeing many healthcare professionals in a variety of settings.

We believe that achieving good outcomes in diabetes is therefore dependent upon these multiple professionals and providers working well together. This is particularly true of primary care professionals who play a critical role on the front line of diabetes care delivery. GPs and practice nurses not only drive prevention and early diagnosis, but are integral to supporting those living with diabetes to manage their condition through optimal treatment and care and avoid admission to hospital, and ultimately enable fully integrated care.

The challenge comes with co-ordinating these many, moving parts of the pathway, while also ensuring access to specialist clinical input where needed; differentiating care for type 1 and type 2; and delivering constant monitoring and good, long-term management.

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Drivers for change

Success of the Quality and Outcomes Framework (QOF)[16] is recognised, but its future is questioned: QOF data shows improvements in care delivery, but many question if targets are sufficiently stretching, or if they are having a direct, positive impact on clinical outcomes. The research also demonstrated limited knowledge or awareness of the newly created composite QOF indicator for the measurement of the NICE-recommended key processes.

"QOF provides a very good baseline in terms of seeing what we are achieving. We weren't organised at all prior to QOF. So in that sense I think it has been a very worthwhile, more educational programme [...] If you actually ask what impact it's had clinically in terms of their complications, it's more difficult." **(GPwSI)**

"QOF, in its time, has been a big changer of diabetes policy in the UK ... The goals that QOF set are not really terribly challenging but it does throw down the gauntlet to primary care, making them more aware of diabetes." **(Diabetologist)**

The GP view

It was agreed that while diabetes remains part of the QOF, it will continue to be a primary care priority. However, the GP group agreed that any future incentive framework should not stop at meeting targets alone – it must focus on holistic patient outcomes.

"There's a sort of perverse incentive we are given through QOF to drive down HbA1c, and that should not actually be the main event in how we treat diabetes."

NICE sets best practice, but implementation is hard to measure: Support from NICE is well regarded, but many question its ability to motivate clinical behaviour change on the ground.

"I think they [NICE guidelines] are a useful tool because they show doctors what they should be doing and doctors tend, in my opinion, over time to end up adhering to them. But it is a long process [...] and I think there is the feeling as well that they're NICE guidelines but in the real world we've got money constraints, we've got capacity constraints etc." **(Journalist)**

"NICE guidelines have been effective in terms of cost-effective diabetes care but they have not perhaps driven change in terms of prescribing. The guidelines have outlined when and when not to use the new agents and that's been helpful. But I wouldn't say that they have driven a lot of change." **(GPwSI)**

The GP view

Feeding into NICE guideline and guidance development was considered a challenge – with GPs describing the process as opaque. When guidance and guidelines are developed they are too long and hard to digest.

Action on Diabetes does not go far enough: While considered a valuable statement of intent and ambition, respondents are looking for more support on the practical implementation of good clinical practice in diabetes.

"It's a rehash of the old ones. I think the intentions in there are perfect [...] My question to all the policy-makers will be that you haven't been able to put into place what we had in 2004, 2008, 2012, so what makes you think that 2014 is going to make a difference? It may be a fantastic piece of paper. However, the problem is always the implementation. The document doesn't give you any tools." **(Diabetologist)**

"It didn't change the world and in terms of diabetes care there is more that can be done. I think it's quite encouraging that there isn't just a cry for more money. There are a lot of things that could be done to improve diabetes care which could probably save money. Unsafe care in hospitals which leads to diabetics having further complications when they could have been prevented by having dietary needs made better, for example, could save money [...] I think they would like to see something clear, which stated a war on diabetes like the kind of leadership which currently exists on cancer." **(Policy official)**

The GP view

The evolving national political landscape is seen to be far removed from GPs' daily clinical reality – instead their worlds are shaped by local leaders and patient demand. Action on Diabetes was not recognised at all – most were not aware of its existence.

"... this sort of policy level, this sort of high-altitude change has no meaning to me whatsoever ..."

"... national leaders need to drive a local conversation ..."

Limited knowledge of available policy levers: The QOF, NICE guidance and guidelines, and education programmes were highlighted as the most effective levers to drive change in clinical practice. The research suggests limited recognition for other available levers such as the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS), Best Practice Tariffs or the Clinical Commissioning Group Premium.

Diabetes could bankrupt the NHS if we do not make it a national priority.

The political challenge

With an ageing population and rising patient expectations, coupled with limited financial resource and continual scientific advancements, Government and the NHS are faced with difficult decisions every day.

Allocating time, resource and political capital to achieve the best possible outcome for patients is an ongoing challenge, and Government commitment to the prevention of ill health and the management of long-term conditions more broadly is welcome.

However, there is evidence to suggest that diabetes' status as a national clinical priority is diminishing.

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The reforms introduced in 2012 led the NHS away from disease-specific targets and frameworks, and instead towards a focus on improving general outcomes, driving system-wide change, and a renewed public health drive. Perhaps an unintended consequence of this shift has been the loss of centres for developing and maintaining condition-specific expertise and knowledge. With the amalgamation of NHS Diabetes into NHS Improving Quality, and the broadening of the National Clinical Director's remit to include obesity, there is an ever-growing risk that policy for diabetes is being lost or diluted.

It is clear that poorly managed diabetes leads to serious, multiple and costly complications. If we continue as we are, it is estimated that in 2035 we will be spending a staggering £13.5 billion on complications – a proportion of which is likely to be entirely avoidable.

It is therefore imperative that diabetes – and those 3.2 million people living with the condition – becomes a critical priority for Government, the NHS and its partners.[17]

It is this landscape which inspires this overview of where those closest to diabetes policy and clinical practice stand.

5. Looking to the future: a consensus of views

A number of issues emerged where there was a consensus on the changes required in the system to improve the treatment and care available to people living with diabetes.

Support in primary care

1. Local clinical champions to support CCGs in designing diabetes care services

Local clinical leadership is a critical success factor in achieving good commissioning for diabetes. Local clinical 'champions' must work alongside CCGs to help create a locally tailored service that incorporates the latest best practice and medical innovation and meets the broad spectrum of needs of people living with diabetes.

2. Preparing the workforce for the diabetes epidemic

The GP workforce is changing. According to the Department of Health's GP Taskforce, 54 per cent of GPs over the age of 50 are intending to leave direct patient care within five years. With 5000 new GPs promised by Government, now is the time to ensure this new workforce is equipped to manage the diabetes epidemic. Professional bodies and medical schools should review their provision of training and continuing professional development in diabetes, and ensure all GPs have the knowledge and skills to diagnose, treat and manage diabetes.

3. A future incentives framework for primary care must drive excellence beyond basic standards of care, and deliver a direct impact on patient outcomes

The QOF provides a solid foundation on which to build a mechanism that both drives clinical behaviour change and improves patient outcomes. The QOF needs to evolve in order to stretch clinicians beyond delivering basic standards of care. Any future incentive framework for GPs should have a direct impact on outcomes and support clinicians to better manage their patients in the long term.

Ensuring the delivery of the true integrated diabetes pathway

4. Creation of an integrated, community-led model for diabetes

NHS England aims to support the creation of major new care models that can be deployed in different combinations across England. This research identifies a clear need for guidance on what a good community-led, integrated care model for diabetes should look like. NHS England should work with the diabetes community to develop a framework, outlining the infrastructure, incentives, skills and expertise of a multi-disciplinary clinical team required to deliver this model of care. Healthwatch England should be involved to help ensure this is built around the needs of the patient.

5. Real-world data should be better used to demonstrate the long-term benefits of early investment in the best available medicines and technologies

Manufacturers should work with local clinical champions and CCGs to develop long-term commissioning plans using real-world data on the potential impact of new medicines and technologies on patient outcomes and health budgets.

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National leadership

6. Existing national guidance on diabetes should be aggregated and made available in a clear, concise and accessible format

There is a plethora of national guidance available on diabetes, from NHS England, NICE, professional associations and patient group collaboratives. Access to and utility of this guidance is questioned throughout the research; there is therefore a job to be done in order to rationalise existing materials and produce a single, user-friendly, accessible platform.

7. National guidance for CCGs on the optimal diabetes treatment pathway, and how to put it into practice

CCGs require better support and guidance to lead the commissioning, design and development of local diabetes care services. If care for type 1 and type 2 is to be appropriately differentiated and if services are to meet the often specialist and complex needs of those already living with diabetes, then clear and accessible guidance is required.

8. Diabetes needs a national drive for success

Diabetes service design and delivery is currently being led in the main by those with limited experience or expert knowledge of the condition. The 2013 reforms created a new cohort of commissioners, and with the GP workforce set to change dramatically, it is vital that they are well supported by Government to meet the needs of a large, growing and varied patient population. The dissolution of NHS Diabetes has also left a notable leadership vacuum in diabetes care.

National policy-makers must provide a detailed plan that supports both commissioners and primary care professionals in the day-to-day delivery of a sustainable diabetes service. There is also a clear and identifiable need for a national, clinically-led hub, providing specialist education opportunities; and a forum for ideas generation, advocacy and the sharing of best practice.

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24,000

people die from avoidable diabetes complications each year

The total annual cost of treating diabetes complications is

£7.7 billion

versus treatment costs of only £2.1 billion

Diabetes UK, *Cost of Diabetes*, 2014[1]

There has been a huge increase in largely avoidable complications since 2006

Cardiac failure has increased by

104%

Strokes have increased by

87%

Kidney failure has increased by

77%

Every year there are

1,280

new cases of blindness caused by diabetic retinopathy

The incidence of children with diabetes being admitted with diabetic ketoacidosis – a potentially life-threatening complication that can lead to death if untreated –

has almost doubled since 2005

Over **100 amputations**

are carried out every week due to complications; 80% of these are avoidable

Diabetes UK, *State of the Nation*, 2013[2]

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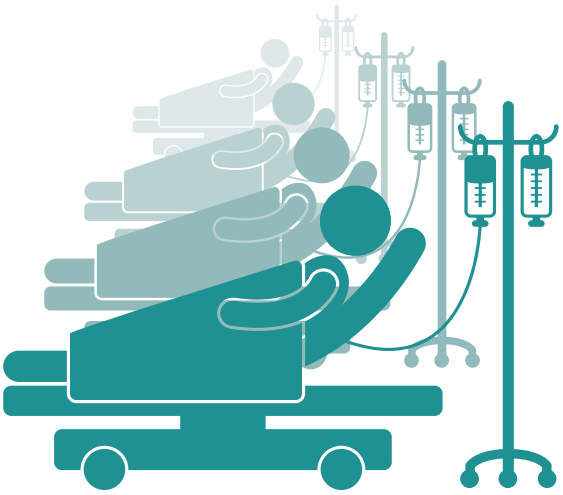

The percentage of beds in acute hospitals occupied by people with diabetes increased to

15.8%,

up from 15.3% in 2012

Inpatients with diabetes admitted to hospital as an emergency

had a longer median length of stay

in hospital (eight nights) than inpatients with diabetes admitted electively (six nights)

Diabetes inpatient specialist nurse (DISN) availability has still not improved

– almost 1/3 of hospital trusts still have no DISN

71.2%

of hospitals had no specialist inpatient dietetic staff time for people with diabetes

National Diabetes Inpatient Audit, 2013[3]

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Association of the British Pharmaceutical Industry
7th Floor, Southside, 105 Victoria Street, London SW1E 6QT
t +44 (0)870 890 4333 abpi@abpi.org.uk

abpi.org.uk

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