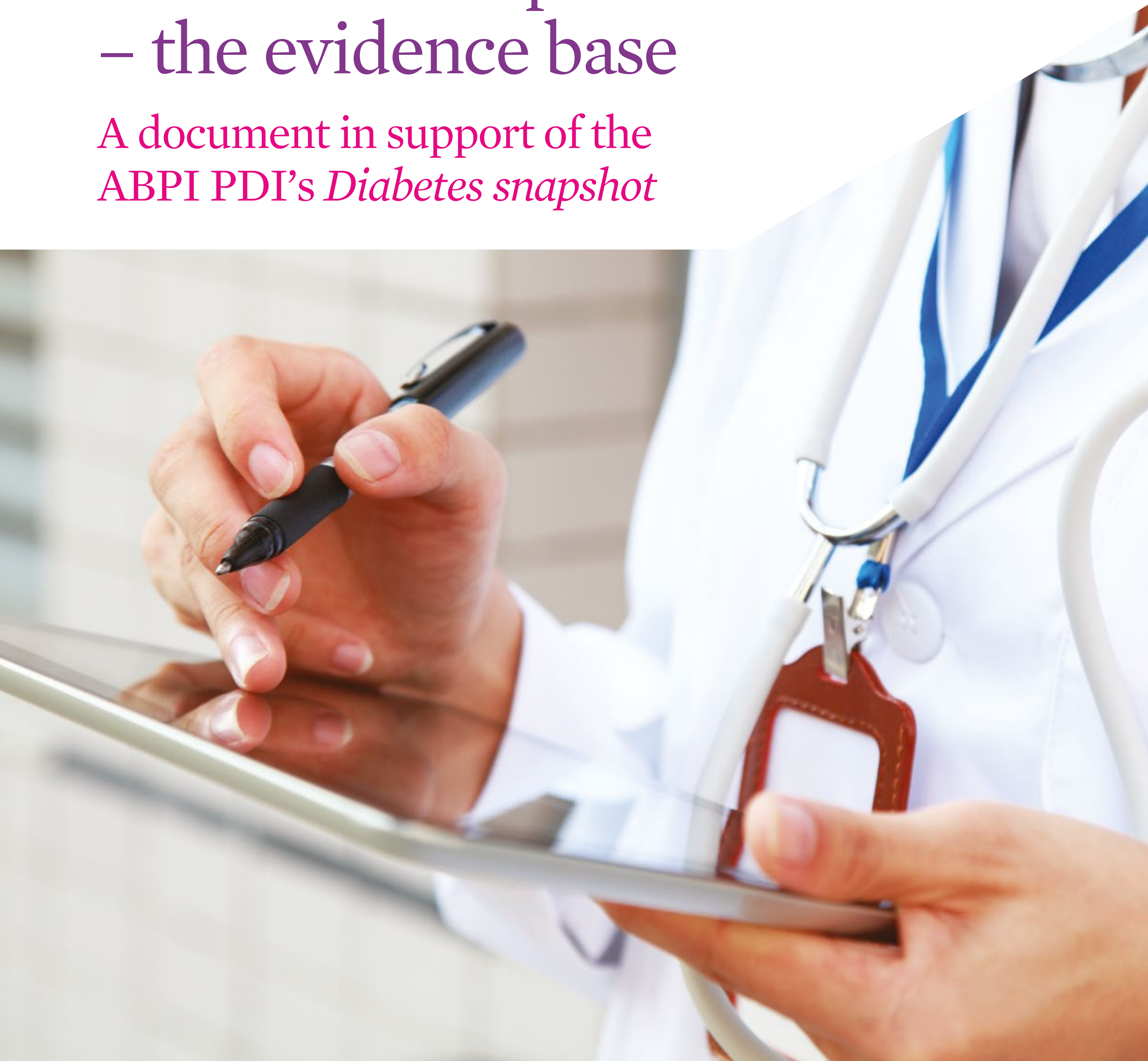
Bringing medicines to *life*

A diabetes snapshot – the evidence base

A document in support of the ABPI PDI's *Diabetes snapshot*



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 –

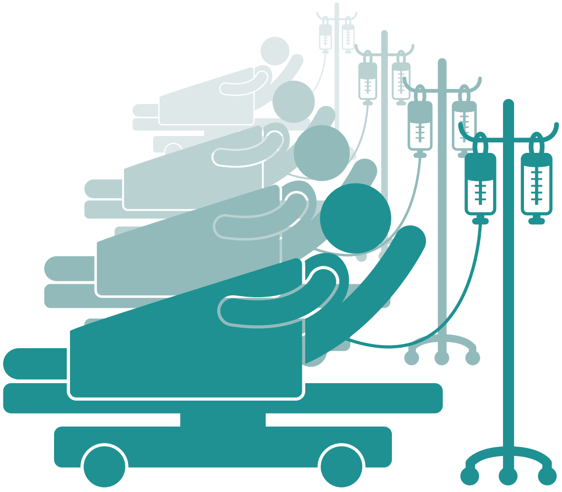
has almost doubled since 2005

Over **100 amputations**

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

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

DIAB-1142173-0000
Prepared March 2015



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

15.8%,

up from 15.3% in 2012

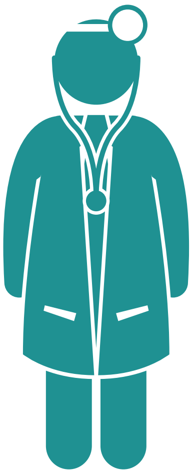
Inpatients with diabetes admitted to hospital as an emergency

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]

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.

Contents

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.

abpi
Bringing medicines to *life*

1. About this project

In March 2014, the ABPI Pharmaceutical Diabetes Initiative commissioned independent research consultancy ComRes to conduct an extensive research project, gathering 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.

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 at a stakeholder round-table event, held 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 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.


PATIENT
DATE
TIME GIVEN
TIME REACTION BEGAN
ADMINISTERED BY

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:

Diabetes as a national health priority

Top findings from ComRes

Participants were asked to consider diabetes' position on the national policy agenda and the impact of recent NHS reforms on national health policy priorities:

- **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 the national standards body for diabetes, NHS Diabetes, seen as a key determining factor.
- **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 a predominantly a public health issue.
- **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.
- **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.

The State of Diabetes Care in the UK, ComRes, September 2014

A declining national priority, but too big for local NHS?

"I don't think you should underestimate the importance of the individuals concerned – if Cameron and Hunt didn't have any interest in this subject [dementia] I don't really think it would [...] be receiving all the column inches and the funding it's getting." **(Journalist)**

The research shows that something important has been lost in national policy-making for diabetes in recent years. In part this is said to be due to the rise of other conditions as political priorities – with cancer and dementia coming up repeatedly as conditions that are perceived to have grabbed political attention and a greater proportion of funding. Diabetes is seen to have once been a direct healthcare priority that has now slipped down the ranks of importance.

"There is a concern that it consumes a large part of the NHS budget, but primarily it does not come across as something being pushed centrally." **(Diabetologist)**

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

"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)**

"I think cancer is a big priority. Obesity has risen up the list. So those are the two main priorities I would say. Also, elderly people with comorbidity and dementia." **(Diabetologist)**

"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)**

Despite this, diabetes is still considered a significant healthcare challenge that should be given higher priority.

"At present the NHS spend on diabetes is £1.4 million per hour, which is about 10% of the annual NHS budget, so it's fairly eye-watering in terms of the impact." **(Diabetologist)**

"There will be massive costs in the future if we don't tackle it. Linked to it is obesity. Obesity leads to type 2 diabetes, type 2 diabetes leads to strokes and heart disease." **(Parliamentarian)**

This suggested vacuum in central government appears to have resulted in a reduced focus on diabetes at local level and a damaging loss of resources. One respondent suggested that so overwhelming is the disease prevalence, Clinical Commissioning Groups (CCGs) feel they need national impetus to make progress.

"It's not as if their [CCGs'] eye is off the ball, but it's almost a feeling that actually diabetes or obesity is such a public health issue and a national issue that it requires attention at a different level, way beyond a CCG." **(NHS manager – commissioner)**

"Around the country there are many diabetes nursing posts that have been frozen. There have been many people working at senior level who have been demoted." **(Diabetes specialist nurse)**

"I think there's probably less resources [available for diabetes] at CCG level in England." **(GPwSI)**

The loss of NHS Diabetes

The 2012 Health and Social Care Act saw an end to an established national policy-making approach, which focused on individual conditions, and replaced it with a move to measuring general population health outcomes. This, combined with a major structural overhaul of health policy-making organisations, saw the national standards body, NHS Diabetes, merged into a single body called NHS Improving Quality (NHS IQ).

A recurring theme throughout this research has been to lament the loss of NHS Diabetes. It was considered a national focus for leadership on the condition, and its break-up is sorely felt, particularly with a loss of important specialised programmes. Respondents felt that the organisation helped set a national agenda, providing impetus to drive up standards as well as being a marshalling centre for clinical education resources.

"NHS Diabetes raised the profile of diabetes, raised the need to give better education to patients and the need to change, the need to improve, and it really upskilled a lot of people and it raised the profile in GP practices. So, patients were diagnosed earlier and they got the help they needed much earlier." **(Diabetes specialist nurse)**

"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)**

"If you went to the website of NHS Diabetes, national guidance and documentation and policies could be posted there. For example, ideas for innovation and change could be shared, educational resources were attached to it – but it's all now been taken apart." **(Diabetologist)**

Create a new clinically-led hub to drive national excellence in diabetes

The dissolution of NHS Diabetes has left a notable leadership vacuum in diabetes. There is 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.

Diabetes is more than just a 'long-term condition'

"It used to be diabetes until two years ago, and now it's all about long-term conditions." **(GPwSI)**

There are hints from respondents that this focus on general outcomes and the merging of policy-making responsibilities has led to a generic operational management for chronic diseases; the prevailing wisdom of which is that these conditions should be managed almost exclusively in primary care. Many of those interviewed were concerned that, although diabetes patients are great in number, the condition can present in a variety of different ways. They felt the complexity of the condition is ill-served by a generalist approach that is more tuned to managing the 'classic' case.

"There is a classic type 2 and there is a classic type 1 and about a third of the patients are about 1.5. So the classification works well for two-thirds of patients but for a third of patients it doesn't work that well at all." **(NHS manager – local area team)**

"There seems to be a bit of a belief that it [diabetes] can be managed by anybody, in terms of not being a specialist. And whilst I appreciate there are diabetes patients that could manage primary care, there are some patients that are very complicated and do need specialist care." **(Diabetologist)**

"When money is tight, the thinking always seems to go back to default that this is a simple problem that can be solved by getting people to eat less and exercise more. They forget that complexity because it's much easier to make simple statements." **(Academic)**

"There is a push to think of long-term conditions as a whole, but I think that they are all very different ... I've been to national meetings where a minister says: 'We need to treat all long-term conditions together', but I don't agree with that. Different conditions need different interventions and specific expertise." **(Diabetes specialist nurse)**

The merging of responsibilities for individual leaders at a national level has also led to a loss of focus. Whereas in the past there was a single senior NHS figure responsible for the condition, now the equivalent has a significantly expanded remit with reduced time and resource.

"I think now the lead for diabetes has got three or four different priorities, and diabetes is just one of them. And I think diabetes has just disappeared off the national agenda." **(Diabetes specialist nurse)**

Prevention agenda – type 1 left out in the cold?

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

On the one hand there are those who see diabetes almost solely as a consequence of poor lifestyle and failed preventative health services. On the other there are those who express frustration with this view and wish to see an acknowledgement of diabetes as an acute condition in its own right.

"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)**

"If you can tackle that [obesity] then you can knock a lot of other things on the head, so to speak." **(Diabetologist)**

"There is a big issue about surgery. I'm not saying that surgery is the cause of the problem (problems with interventions at the individual level) but there does need to be further investment in it." **(Academic)**

"People get type 2 diabetes because they're making bad lifestyle choices and have done for years and years and years, and it is naïve, I think, to expect patients to suddenly realise – whether it's talking to a doctor or a nurse, a dietician, a private care physician – that they have to change the habits of a lifetime." **(Academic)**

"I don't think we are seeing the prevalence in type 1 increasing, but it's type 2 where the prevalence is increasing, which is down to people's lifestyle in a large way." **(GPwSI)**

Some of the respondents perceived prevention of future obesity-related diabetes as an easier and surer route to budget savings than optimal management of those with the condition now. Others felt this focus led to the needs of those with type 1 diabetes being under-appreciated.

"I suppose I'm a bit frustrated that although diabetes is recognised as a health problem […] the response is exhortations to eat less, be thinner, etc. and I think we should distinguish between type 2 and type 1 diabetes as I'm not sure that nationwide there is much understanding of the differences." **(Academic)**

"It seems that obesity is one of the key priority areas, so in a roundabout way type 2 diabetes does come into that. It pushes type 1 diabetes out of it, because that's not linked to obesity." **(Diabetes specialist nurse)**

"Type 1 is lower down the priorities of the Government's agenda. Often diabetes is just seen as diabetes, so it's not really as high up as it should be." **(Diabetologist)**

"A lot of people with type 1 have been regarded in the same boat as those with type 2 – they are very different. People with type 1 have been swept away on a tide of type 2 where they are treated as the same thing, but they are not." **(Diabetologist)**

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

It is clear that most respondents back the notion that all steps toward prevention must be taken and are welcomed, but not at the expense of patients who are currently experiencing acute illness as a result of diabetes, or for those with type 1 for whom obesity and lifestyle are irrelevant as a trigger for the condition. This has manifested itself in policy, which creates simplistic provision for what is a complex illness that needs individual expert intervention to help patients control the many ways in which symptoms occur. The choice must not be either/or – it must be both at same time with equal vigour.

National support for CCGs on what 'good' looks like in diabetes, and how to make it happen

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 services are to meet the often specialist and complex needs of those already living with diabetes, detailed service specifications and commissioning guidance is required.

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?

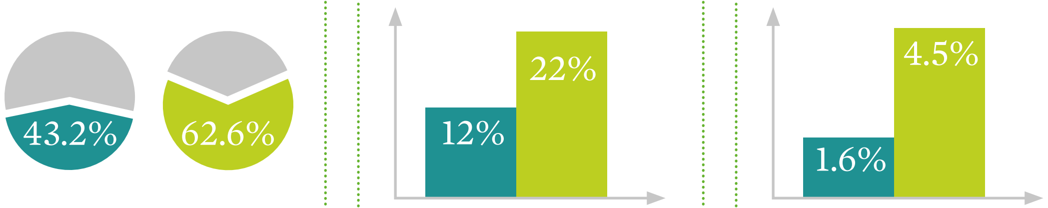
- Diabetes as a long-term condition is acknowledged within Domain 1 of the NHS Outcomes Framework; the Public Health Outcomes Framework; the Cardiovascular Outcomes Framework; and the CCG Outcomes Indicator Set. In early 2014, NHS England published the Action for Diabetes plan, setting out what it intends 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 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.

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 (2014).[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

Top findings from ComRes

Participants were asked to consider NHS performance in the treatment and management of people living with diabetes:

- **Widespread variation in care and outcomes:** Respondents said 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.
- **Evidence of both the exemplary and 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, respondents point to many areas which provide unacceptably low quality care and produce poor patient outcomes.
- **National and local leadership vacuum:** Diabetes specialists highlight the break-up of NHS Diabetes and the devolution of power to local Clinical Commissioning Groups as major contributing factors to ongoing variation in diabetes care and outcomes.
- **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.

The State of Diabetes Care in the UK, ComRes, September 2014

A pessimistic outlook on UK outcomes

The majority of those interviewed – including both clinicians and non-healthcare professionals – were pessimistic about the current state of diabetes care in the UK. Data from the most recent National Diabetes Audit[7] provides extensive evidence of this pessimism, highlighting areas of diabetes care in need of significant improvement.

‘Unacceptably high’ complication and amputation rates were highlighted in particular by respondents.

“We’ve got a rise in the complication rates, so whatever’s happening in terms of trying to lower the complications isn’t happening, so it’s not looking good.” **(Patient group)**

“Widely-publicised figures show that we are not particularly good at doing the basics ... This is reflected in the measurement of hard outcomes in terms of complications, needle replacement therapy (NRT) levels, mortality rates and amputation rates that are all higher than acceptable.” **(Diabetologist)**

“Preventable complications caused by diabetes are much more expensive than good care.” **(Diabetes UK, *State of the Nation 2013*, 2014)**

International comparisons were also made by respondents, highlighting the NHS’ poor record on delivering the nine NICE-recommended basic care processes. Whilst it is not appropriate to compare differing international healthcare practices directly, many respondents felt that the NHS performed poorly in this area in comparison to other countries.

"I think if you look at the UK compared to Europe, we do poorly. I think we are getting better in type 1 for our children and their general outcomes but I don't think we are getting better for adults particularly." **(Diabetes specialist nurse)**

"If you compare it internationally, the UK looks pretty terrible. The measure of glucose control over time is much higher in the UK. People aren't getting all of the basic healthcare checks that they should be getting." **(Patient group)**

Variation in care and outcomes

While it is accepted by respondents that, overall, outcomes achieved in the NHS in England could be better, this untempered pessimism is not characteristic of all stakeholders. Instead the research highlights regional variation: an assessment that is in line with long-standing reporting from NHS England, the Department of Health and the wider advocacy community.

"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)**

"Some patients are likely to get very good service from GPs and nurses and possibly dieticians in the community who are very well informed. But I think it is a bit of a lottery depending on which GP practice you're registered with." **(Diabetes specialist nurse)**

"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)**

Importantly, this variation in care and outcomes is not said to be restricted to one specific part of the pathway. Instead, the research suggests differences in the quality of early intervention, ongoing management, and specialist and hospital care for people with diabetes.

Variation in patient education

"There's a lot of research which shows that more education at the point of diagnosis – and particularly being given more intensive treatments at the point of diagnosis – will improve outcomes for the long term. Some places in the UK are up to speed with this and some places in the UK aren't." **(Patient group)**

Variation in foot care

"In terms of foot care there are clear variations in outcomes: in inpatient diabetes care there are huge variations in outcomes." **(Diabetologist)**

Variation in access to specialist care

"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)**

Dissolution of NHS Diabetes and devolution to CCGs

The 2013 healthcare reforms transformed the way in which diabetes treatment and care is commissioned, managed and led across the NHS.

The two changes that drew particularly strong opinions in the research were the shift of commissioning responsibilities for secondary care services to CCGs; and the dissolution of the national diabetes leadership body, NHS Diabetes.

NHS Diabetes previously acted as a hub for professional and patient education resources, national policy development and advocacy. In an attempt to shift emphasis away from condition-specific structures to a more system-wide outcomes approach, the 2013 reforms pulled NHS Diabetes into the newly formed NHS Improving Quality (NHS IQ).

Clinicians and non-healthcare professionals alike suggested that the creation of CCGs, coupled with the dissolution of NHS Diabetes, had made a significant contribution to variation in the prioritisation of diabetes across the NHS. Without the national leadership drive from NHS Diabetes, CCGs have been given the responsibility to deliver local excellence in diabetes treatment and care. The research suggests that this has led to a mixed picture in the quality of care and outcomes, with some CCGs not prioritising diabetes in their commissioning plans.

> *“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)**

> *“Because not every commissioning group has necessarily made diabetes a priority there’s a deficiency in the actuality of policies that actually deliver the services at a primary care level and at a secondary care level.”* **(Diabetes specialist nurse)**

Clinical champions: plugging the gaps

The perceived lack of national leadership and inconsistent local prioritisation of diabetes could suggest the need for more local diabetes advocates or ‘clinical champions’.

The research reported examples of diabetes experts acting as local clinical champions, mobilising their local networks and relationships with commissioners and providers to advocate the prioritisation of diabetes. However, as before, this is by no means a consistent picture.

> *“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)**

> *“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)**

"If you have good local clinical champions in your area who have built up good relationships and good networks, then you can get a prescribing list that reflects the care that should be happening." **(Diabetes specialist nurse)**

What is clear is that where these clinical champions are in place, they are successfully influencing commissioning decisions and having a positive impact on those living with diabetes in that particular area.

As before, variation remains a challenge. These examples represent single pockets of success, but for a diabetes clinical champion model to have a consistent impact, it will need both local and national support.

Where a clinical champion is not in place, there are reports of a diabetes policy vacuum. Concerns were raised that in such cases, important decisions are being made by people who may not be fully informed or aware of the outcomes of their decisions.

"Because not every commissioning group has necessarily made diabetes a priority, there's a deficiency in the actuality of policies that actually deliver the services at a primary care level and at a secondary care level." **(Diabetes specialist nurse)**

"But when you don't have clinical champions [...] then you get to the point of having administrators and other people making decisions that are not always linked to the clinical need in a certain area. So I think promoting and supporting clinical champions is really important." **(Diabetes specialist nurse)**

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 latest best practice and medical innovation and meets the broad spectrum of needs of people living with diabetes.

Need for a national drive to tackle variation

To combat these local variations – be they down to an absence of clinical champions or the commissioning decisions of CCGs – many stakeholders called upon Government to renew the national drive to tackle diabetes. Respondents felt that this would be the only way to ensure that individual CCGs do not de-prioritise diabetes treatment and care.

"[The Secretary of State] would say we've introduced a devolved system so it's up to individual CCGs. That's fine, but we've got a national health system, and if there are very, very great disparities in care between different parts of the health system, it's hard on those people who are in CCG areas where the care is poor. I would have thought that in a national health system, somebody ought to have an overview role that says that if there's clearly a CCG that's making a Horlicks of this, what needs to happen next?" **(Patient group)**

Some healthcare professionals (HCPs) and managers highlighted the success of the National Retinal Screening Programme, as evidence of how a national intervention can impact positively on areas of care need.

"What's been helpful is the impact of the National Retinal Screening Programme whereby, because that's rolled out nationally and works relatively well, patients tend to attend when they're prompted to have their eyes tested and therefore you can clock problems early." **(Diabetologist)**

"Retinal screening has made a huge difference. If you compare it to 20 years ago, retinal screening is now widespread in the country and I think we don't see as much blindness [linked to] diabetes as we did 20 years ago." **(NHS manager – local area team)**

"I think in the longer term, one of the successes that I see is things like eye screening – that's a national programme that's a big improvement that I've seen over the years that I've worked in diabetes. I'm not sure what the uptake is for eye screening, but it seems to be better organised and there are better facilities for eye screening." **(Diabetes specialist nurse)**

Despite HCPs praising the work of clinical champions in improving standards, this is ultimately seen only as a short-term solution. There will inevitably be areas where improvement in diabetes care is required, and those clinical champions lack the capacity or resource to drive change. Many of those interviewed, therefore, advocated the need to reappraise the use of national goals for diabetes to eliminate unacceptable levels of variation and bring all areas up to a minimum standard of care.

Diabetes in primary care

Momentum in healthcare policy and Government ambition has been in the direction of primary care, with GPs becoming increasingly central to the design and delivery of care services. The 2013 reforms led to a shift in secondary care commissioning responsibilities to GPs, as part of CCGs; and importantly a rebalancing of care away from acute centres, towards community care settings. More recently NHS England's *Improving General Practice: a call to action,*[8] alongside its *Five Year Forward View*, have both indicated an intention to pursue new models of care, placing even greater emphasis on the role of the GP in primary and community care.[9]

The research suggests that this shift towards primary care has had a dramatic impact on the state of diabetes care in the UK. For many it has been seen as a positive move, but its execution has been considered 'disappointing'. Specialists reported concerns that the primary care workforce has not been adequately prepared for addressing the often complex needs of diabetes patients.

"Overall I think it was a fantastically good move. However, primary care was landed with 100,000s of diabetic patients without being equipped or prepared to do so – this was at a time when newer agents were coming out: you can't exaggerate how difficult a problem that has been for diabetes care." **(Patient group)**

"The problem with diabetes is that it's been shifted to primary care and the training probably wasn't there when it first shifted." **(Diabetologist)**

Building the right workforce: “confidence and competence”

A lack of national guidance is not considered to be a problem by respondents. Overall, healthcare professionals tend to agree that there is sufficient high-quality guidance for GPs and practice nurses on how to best support people living with diabetes.

In spite of this acknowledged abundance of high-quality guidance available, specialists and patient groups expressed concerns that GPs and practice nurses may not be sufficiently confident, or indeed competent, to support people living with complex diabetes.

This, they feel, could be the result of a number of factors, but suggest a lack of education and formal training is at the heart of the problem. It is clear to many that simply having guidance in place is not sufficient to ensure full and accurate implementation. There is a suggestion that more clinical and government supervision in GP practices would be desirable to ensure the delivery of a good standard and continuity of care.

> *“Sometimes healthcare professionals 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)**

> *“We’re now getting situations where patients get reviewed by practice nurses in GPs’ surgeries who haven’t had any enhanced diabetes training. […] So, in addition to other general practice type work, they’re now being expected to perform six-month annual reviews on diabetes patients without having had the formal training to know what to look out for.”* **(Diabetologist)**

> *“I think, generally, diabetes centres on the whole have got good skills. But, once they transfer to GPs’ practices that skill is not properly monitored and sometimes people get very poor treatment. If I was going to do anything I would put much more clinical and government supervision into GP practices to ensure there was continuity and a good standard of care. At the moment there isn’t.”* **(Diabetes specialist nurse)**

> *“To be honest, where it usually falls down is practice nurses as they usually want to keep the patients within a practice and they don’t see that there’s a need for referral and they think that they can do it.”* **(Diabetes specialist nurse)**

Subsequently, there is a feeling among specialists that there needs to be a higher level of training in primary care to ensure that all practice nurses are confident in delivering the key care process for diabetes, and that GPs have the expertise to deal with more complex cases.

> *“I would like competency-based training for healthcare providers.”* **(Diabetes specialist nurse)**

> *“I think it’s very much a question of: if you want to improve diabetes care, then you need to have some core knowledge which everybody needs to understand. This can be very simple like knowing how to do the 15 healthcare checks, what are the drugs etc. I think everybody in any healthcare training should know the core of diabetes care.”* **(Diabetologist)**

> *“I think the ongoing education should be another focus, or bring back the nine care processes so at least patients know what to expect and get it every time. So we need to educate both the healthcare professionals and the patients.”* **(Diabetologist)**

Diabetes as a professional focus: "unpopular and not prioritised"

"In general practice diabetes is an unpopular area and not prioritised." **(Patient group)**

In addition to a perceived absence of training opportunities in primary care, specialists and patient groups identified a fundamental lack of interest amongst some GPs as a reason for some of the variation in quality of care.

These stakeholders suggest that GPs already have such a large remit, and in addition to their own areas of clinical interest, the risk is that diabetes will fall further down the list of priorities.

"When I do clinical supervisions, in a way I'm supervising the wrong doctors because the GPs who are interested come and we really have a very constructive hour discussing their most difficult case. But, of course, only a third of the GPs turn up and you suspect the two-thirds who don't are those who really need it and they're not engaged." **(Academic)**

In the worst case scenario this reported lack of interest is said to lead to people with diabetes not accessing the basic but essential key processes of care. This is in spite of the fact that GPs are financially incentivised to do so via the QOF.

"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)**

"We need to make sure that people with diabetes have a proper, full diabetes check at least annually, which is not happening at the moment." **(Professional body)**

Ultimately, if people living with diabetes are expected to access the majority of their treatment and care in a primary care setting, these skills gaps need to be filled. The research suggests that standardising and enhancing the training and education of primary care professionals must be among the highest priority interventions, be it led by the NHS locally or centrally driven by Government or professional bodies.

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 5,000 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.

Education at the critical point of diagnosis

“Despite improvements over the past few years, [patient] education remains poor.” **(Diabetologist)**

“I think the biggest gap is in the attitude of some clinicians in terms of working with and supporting people with diabetes to self-manage.” **(Patient group)**

In addition to guidance available to healthcare professionals, there is widespread agreement that education and guidance for patients is essential to improving outcomes in diabetes. This education becomes critical at the point of diagnosis; optimising outcomes at this early stage can have important legacy effects.

“There’s a lot of research which shows that more education at the point of diagnosis, and particularly being given more intensive treatments at the point of diagnosis, will improve outcomes for the long term. Some places in the UK are up to speed with this and some places in the UK aren’t.” **(Patient group)**

Many feel, however, that education at the point of diagnosis is poor and does not fully prepare a patient to manage their diabetes successfully at home and in the long term. It is suggested that this may be due to a lack of time or knowledge amongst primary care professionals of how to ensure that patients are fully informed and engaged with their diagnosis and the long-term management of their condition.

“There are barriers around healthcare professionals not understanding how to support people to manage their condition better. So there are training and educational implications for both patients and their families and also for staff who deliver the services.” **(Professional body)**

Diabetes specialist nurses are critical of the low number of patients who receive structured education on self-management at the point of diagnosis. This group are strong advocates of the impact this education can have on outcomes, but suggest that it is underused in current practice. Diabetes UK reported in 2014 that only 4.2 per cent of all people with diabetes are currently being offered structured education opportunities.[10]

“The last audit told us that as little as 5% of people with diabetes have access to structured self-management education, and unless we do something about increasing access and availability and this is seen as part of the whole care pathway, then we are not going to make inroads into improving care.” **(Diabetes specialist nurse)**

“Things like structured self-management education, which is an integral part of care, is [sic] not currently being utilised as much as it should be.” **(Diabetes specialist nurse)**

Enabling self-care

Respondents suggest that enabling self-management might be resource-intensive, but it is central to improving clinical outcomes. They also suggest that more effort should be applied to developing innovative solutions to overcoming these time pressures.

Group consultations with diabetes specialist nurses on structured self-management

"Things like group consultations could be effective, because often people say that the barrier to implementing things like self-management is that we don't have time. Normally you would see a person for half an hour. If you invited eight people for two hours you have saved a lot of time resource and each person is getting two hours instead of half an hour." **(Diabetes specialist nurse)**

Training non-healthcare professionals to provide patients with self-management support

"We need to think about the role of non-registered HCPs in providing support to self-management, as the demand will always be too much for HCPs to meet. I mean training up people who are not HCPs to provide parts of that care [...] They need to be trained, and it needs to be quality assured and standardised." **(Diabetes specialist nurse)**

Recognising the value of pharmacists

"Some people I know fear going for their annual check-up with their GP because their GP is going to tell them off – it doesn't lead to an open and honest discussion with a GP about things that might be affecting their lack of diabetic control. But within the healthcare system there are people who are trusted enormously by patients and are quite prepared to tell them anything openly and honestly, and that's pharmacists. Pharmacists, to me, are much better educators than GPs. Using pharmacists and the trust that pharmacists have in the eyes of patients could be revolutionary." **(Parliamentarian)**

Better ways of working: "shared goals, shared values"

The fragmented nature of diabetes care is considered to be one of the great barriers to improving outcomes in the UK.

NHS England's *Five Year Forward View*[11] acknowledged a significant divide between GPs, hospitals, mental health services and social care, even though many people now require more of these services during the same episode of care. This is especially true of people living with a long-term condition.

"Care would be greatly improved if there was a fully integrated service that had one budget, everybody would be working for the same organisation. It is getting worse and worse, now we have got tenders going on all over the place, services being broken up, people like [service company]... coming in and cherry-picking aspects of diabetes care which just fragments it even more." **(Diabetes specialist nurse)**

The vast majority of healthcare professionals and NHS stakeholders say that they are concerned by the lack of communication across the diabetes care pathway. Respondents predominantly referred to a macro disconnect between primary and secondary care. However, they also identified a lack of communication between doctors and nurses, and other specialists in the pathway including optometrists, ophthalmologists, dieticians and psychologists.

"[We need to] improve integration around primary and secondary support of diabetes, with the aim of ensuring those who can have their care delivered safely in the community are cared for in that environment, but equally there are skills within the environment to recognise those individuals who would benefit from secondary care." **(NHS manager – provider)**

"... optometric practice has often not been seen as part of the healthcare team and so they don't have access. [...] If the patient is referred for whatever condition, the hospitals do not most of the time write back to the optometrist, so the optometrist doesn't know what was done, what was found, what wasn't. They don't know if a sign that they saw has been investigated in the past so the only option they have is to refer them again – so the patient is bounced back and forth, which is not only an inconvenience for the patient but expensive and resource-intensive." **(Professional body)**

Moreover, healthcare professionals expressed a fear that this lack of partnership working and cross-pathway communication has left a vacuum of accountability and responsibility for the delivery of high-quality care across the system.

"At the moment no one takes overall responsibility for a patient's outcomes." **(Diabetologist)**

"[The] problem is that everyone has conflicting aspirations. The time has come to say what patients need and want and get them to the centre of care because that's the uniting feature. What produces better outcomes for patients and how do they feel about it?" **(Patient group)**

"For me the biggest problem is that we have tried to tackle diabetes within our organisations, and we have struggled to do it across organisations. The biggest change that potentially could be made is if the number of organisations who work with people with diabetes agreed a single agenda." **(Diabetologist)**

"We need a direction of travel, shared goals, shared values." **(Diabetes specialist nurse)**

Overcoming the barriers to an integrated service

Clinical collaboration

Most agree that the quality of diabetes care and outcomes increases dramatically when strong clinical partnerships are in place. Respondents defined best practice as a coalition of healthcare professionals coming together to work to a single agenda across a single pathway of care.

"It's successful when you have all the different disciplines coming together – from the nutritionist, the chiropodist, the GP, the diabetic nurse [sic] – all of them being on hand and able to intervene as necessary and able to help the person with diabetes control their condition." **(Parliamentarian)**

"Certainly in my area we've created, with the support of the Primary Care Trust and hopefully the Clinical Commissioners, a seamless service where we're responsible for training practice nurses that deliver care in the hospital base. Teams go out, including myself and other consultants, to conduct clinical supervision and support primary care teams on how they approach diabetes, so that's fantastic." **(Academic)**

"In Wales we have a unified primary and secondary care healthcare system. Our GPs and hospitals work for the same organisation. We're not in competition here, we're working together across our patches geographically. There really is a big difference in the way that we provide our care." **(Diabetologist)**

Critically, healthcare professionals emphasise the importance of putting the patient at the heart of this collaboration, ensuring that all those involved are working together towards a shared goal. It is felt that by enhancing the relationship between the person living with diabetes and their healthcare team, clinical outcomes and overall experience can be greatly improved.

> *"If you build a relationship with a patient, and you are supporting them and making those decisions together, have a joint objective and building that working relationship, then you both have a commitment to each other, and that builds a better therapeutic relationship to achieve better outcomes. And there is a lot of evidence to show that how you build up that therapeutic alliance will make a difference."* **(Diabetes specialist nurse)**

Data sharing

One the most fundamental tenets of integrated healthcare is the value of data. Government has placed significant emphasis on improving the quality of data collected in the NHS and how it is shared and used.

A team dedicated to information sharing, data and technology has been set up within NHS England; and the Secretary of State Jeremy Hunt has tasked the NHS with becoming paperless by 2018. Moreover, new initiatives are being trialled and tested on better ways to collect, share and analyse patient data in order to drive improvements in commissioning, care and outcomes.

In spite of this existing collective will, many of the healthcare professionals interviewed reported the difficulties they experience in sharing data with their clinical colleagues, inhibiting their ability to build cohesive clinical partnerships.

> *"Part of the difficulty of bringing together the teams is sharing data. It may be the case that one group has some data that will be useful and that won't necessarily be shared [...] Data sharing is one of the key things, and that will facilitate the conversations that will improve quality of care."* **(Diabetologist)**

> *"We have optimal coherent tomography, which enables a 3D photograph [...] It can be extremely useful in patients with diabetes as well as patients with other suspected retinal conditions, but we can't send the images. By not being able to do that electronically loses a huge amount of information and doesn't help the ophthalmologist prioritise the referral because they can't see the image that the optometrist saw."* **(Professional body)**

Around the country there are examples of best practice in building these clinical partnerships and alliances among HCPs and patients. However, like much of diabetes care, the quality of these partnerships varies greatly. Many feel, therefore, there needs to be more effort at a national level to examine key successes and replicate these in areas where care is more fragmented.

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, 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.

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);[12] it remains one of the leading causes of blindness in people of working age (2014);[13] and results in 600,000 excess hospital bed days (2013).[14]

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).[15] 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 Head of the National Audit Office, Amyas Mors, stating quite clearly in 2012 that the Department of Health had *"failed to deliver diabetes care to the standard it set out as long ago as 2001"* (2012).[16] 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).[17]

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.[18] 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.[19]

Medicines and technologies

Top findings from ComRes

Participants were asked to consider the role that medicines and technologies can play in the management and treatment of diabetes:

- **Strong innovation in pharmacology:** Respondents recognised that there is a broad range of treatments and technologies available to treat diabetes in the best possible way.
- **Knowledge to support optimal prescribing is lacking:** Barriers to the use of new medicines include a lack of knowledge and confidence amongst primary care professionals on how to build these new medicines into a patient's treatment plan.
- **Local prescribing guidelines limiting clinical freedoms:** Many are critical of the cost-cutting imperative, which is said to be 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.
- **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.
- **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 by many to be more cost-effective in the long term.
- **Technology has the potential to deliver, but uptake is poor:** The use of insulin pumps, continuous glucose monitors, telehealth, smartphones and apps is said to dramatically improve the lives of people living with diabetes. However, many say that adoption in the NHS needs to be improved, with patients able to access more sophisticated devices that are fully integrated into the NHS.

The State of Diabetes Care in the UK, ComRes, September 2014

Strong innovation in pharmacology

"For medicines, I think that development is fast and strong, especially for type 2 diabetes." **(Diabetologist)**

The research acknowledges strong innovation in pharmacology for diabetes. Specialist clinicians refer to a sophisticated range of medicines available to them, enabling the development of tailored treatment plans to meet a patient's specific needs.

In particular, new classes of medicines, for example GLP-1 agonists and DPP-4 and SGLT-2 inhibitors, are considered a welcome evolution in the range of treatment options available. This is said to have afforded clinicians and patients greater choice, above and beyond standard classes like sulfonylureas.

"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)**

Diabetes as a complex condition

> *"Prescribing habits in primary care are poor. For many patients they are kept on very basic drugs for a very long time even if their glucose levels are not responding."* **(Patient group)**

Specialist clinicians highlighted the fact that some GPs find it hard to use these new medicines in practice, particularly when prescribing for a complex case, within an already complex pathway.

While medical innovation and advancement is welcomed by healthcare professionals, it does then mean that the prescribing pathway becomes more varied, with multiple options for the clinician and patient to consider.

> *"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)**

> *"SGLT-2s and GLP-1s and newer drugs are not being endorsed. It is still just 'Let's carry on with sulfonylureas'."* **(GPwSI)**

> *"The number of medicines available to patients has risen dramatically in the past few years. That's great as it can help us decide what is best for the patient, but I think it can be very confusing for patients and for professionals, so that needs to be done in a way that aids understanding."* **(Diabetologist)**

If the NHS is to enable optimal uptake of new medicines, it is vital that healthcare professionals know when to best prescribe these medicines as part of a tailored care plan. Although specialists demonstrated good awareness of these new classes of drugs, they expressed concern, as did patient groups, that GPs are either unaware of their existence or lack the expertise to put them to use.

> *"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)**

Reports of this apparent knowledge deficit in primary care led many to express concern that not all patients are being prescribed the best available medicine to meets their needs. More education and training for GPs is therefore seen as necessary to ensure that patients are able to access the right treatment for them, at the right time in their pathway.

> *"We've come to a point where we might start medication and need to stop it and try something different because it is not working, but some GPs get frightened and patients get left on them and they may not be being very effective."* **(Diabetes specialist nurse)**

Clinicians denied freedom in prescribing

The financial challenge faced by the NHS is well documented. Tasked with making efficiency savings of £50 billion by 2020/2021, the NHS is working to an increasingly tight budget. Government and NHS

England have been clear: this efficiency drive is about achieving and delivering more, but for less. By doing things differently and using innovation in the right way, the aim is that services will deliver better outcomes while at the same time becoming more efficient and cost-effective.

However, commissioners and managers across the NHS now have to balance the urgent need to save money and to deliver excellence in care and outcomes.

The research suggests that in diabetes, the situation is no different. Respondents referred to local prescribing committees preventing clinicians from prescribing certain NICE-approved medicines if there are cheaper options available.

> *"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)**

> *"I think sulfonylureas is in some cases appropriate for someone who is motivated with a good lifestyle and not overweight, but not for the majority of patients. I prefer to use newer medicines such as gliptins but they are often viewed as being too expensive. Because of the unit costs of such drugs they are not favoured by the local commissioning groups."* **(GPwSI)**

Some note that access to these more effective but occasionally more expensive medicines can vary. This might be dependent on whether there is a local clinical champion advising the CCG on the cost-effectiveness of that particular treatment, technology or class of medicine.

If there is no local clinical champion, or a GP is not actively fighting for better prescribing guidelines, then respondents said that less effective drugs may be prescribed by default. Importantly, this view is also acknowledged by those working within CCGs.

> *"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 outcomes for 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)**

Getting it right for patients early

> *"We don't have the balance right. Although some of the medications are more expensive than we like, some of the benefits that they can produce are worth a fortune."* **(Patient group)**

Specialists are particularly critical of CCGs that take a short-termist view when it comes to investing in treatment and care. Respondents referenced studies that demonstrate how intensive early intervention in diabetes can significantly improve patient outcomes. Furthermore, they note that these studies show that by opting for cheaper, but less clinically effective medicines, the NHS ends up spending more in the long term, treating complications that arise from poor management earlier in the pathway.

> *"As far as treatment is concerned, for type 2 diabetes, the medicine management people all the time are telling us to use cheap drugs. That is all well and good but actually when you take into consideration the challenges that occur using cheap drugs, it actually becomes more expensive. The government has a short-term view of diabetes. Use cheap drugs now and risk the complications later which are hugely expensive, or treat the person now with effective treatment which might be a bit more expensive, but could save those long-term complications in the future."* **(Diabetes specialist nurse)**

The research therefore shows strong support for greater investment, early in the pathway. Respondents said that this will encourage better patient outcomes and an improved patient experience; and potentially protect the patient from developing serious and costly complications 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)**

National intervention

Due to this reported variation in prescribing, patient groups in particular advocate more national leadership and guidance on the types of medicines that should be used in order to achieve the best possible outcomes for the patient, and provide value for money to the NHS. A national push was considered imperative; without it, prescribing guidelines as determined by CCGs are likely to continue demonstrating a tendency for short-termism.

> *"If what we would be saying to GPs is: 'Try your patients on this fancy drug, because it will save the whole system mega-bucks in 15 years' time, but it's going to blow your pharmaceutical budget next week', it isn't going to happen unless there's some kind of requirement that makes it bad practice for a GP to let someone bump along with a blood glucose level of 9 or 10 destroying their organs."* **(Patient group)**

To ensure that innovative new treatments make it into the hands of those living with diabetes, GPs and CCGs are said to need more guidance on best practice prescribing and the impact it can have.

> *"My concern is that the headline prices for these [diabetes-related devices] are really very high and the evidence that they actually result in better outcomes is not there. So when you do a cost-effectiveness analysis, such as what NICE does [sic], the cost comes out as being so high that it's just not fundable on the NHS."* **(Academic)**

GPs require more support on how and when to best prescribe these new medicines as part of an increasingly complex diabetes care pathway. CCGs need to have a better understanding of how an investment in the short term can deliver on outcomes and value in the long term, benefiting not only those living with diabetes, but the NHS and ultimately the taxpayer.

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.

Recognising the potential impact of technologies

The use of technology in the treatment and management of any long-term condition, but particularly diabetes, has the potential to transform people's lives. Insulin pumps and continuous glucose monitors (CGMs) – technologies most often cited in the research – can help people manage their condition on a day-to-day basis, giving them the freedom to live full and independent lives.

While healthcare professionals recognise that these technologies are not appropriate for everyone, there is the view that provision is "ridiculously low" in the UK, particularly when compared to the USA and continental Europe.

> *"The provision of new technology like insulin pumps and CGMs is ridiculously low in this country. We're talking 6% max., compared with figures like 30% in Europe and America. So, in that sense, the care is not very good."* **(Patient group)**

> *"For type 1 we are underachieving in terms of the number of patients on pump therapy, and the biggest new development that we need in pump therapy is the closed loop system."* **(Diabetologist)**

The research also suggests the technologies currently in use in the UK could be more sophisticated, with other countries opting for more advanced devices that fundamentally improve the patient experience.

> *"We are able to access insulin pumps for people with type 1 diabetes fairly easily and we do have a range of different pumps available. However, the patients want something easy and not too conspicuous. In my experience, I know that patients want something easy, so I don't use the technology that is available."* **(Diabetes specialist nurse)**

> *"For the potential survival of a person with type 1 diabetes, the role of medicine and new technology is incredibly important. I think that the technology has lagged behind other technology in society. A blood glucose meter, for example, is decades behind."* **(Patient group)**

> *"In America there are pumps that measure the glucose level and give the dose without a second thought."* **(Patient group)**

The use of telehealth in diabetes is cited as an innovation that could greatly enhance patients' ability to better manage their diabetes. However, this is again seen to be underused.

> *"In terms of technology we have got a lot of near-patient testing going on and I think certainly that more patients are going to manage things by telehealth."* **(GPwSI)**

"It is something I've been reporting on forever – isolated cases of good care using telehealth – but you don't hear about access for everyone, so I think there is still a lot of room for making aspects of telehealth more widely used." **(Journalist)**

Barriers to uptake

The high cost implication is often cited as a reason for why technology is underused. Some suggest the need for a more developed evidence base, highlighting the potential long-term value to decision-makers and opinion-formers in Government and the NHS.

"Insulin pumps, continuous glucose monitors and things like this are starting to make a big difference for type 1 patients, but it's too early to know whether it is making a difference regarding long-term complications." **(NHS manager – local area team)**

"I think cost is quite a big issue. [...] The NHS has a finite amount of money so I don't think you can start saying that everyone should have everything. I think the way that it's going is reasonably okay as long as the specialists have input into these area prescribing committees or hospital boards or whatever, and as long as it's not led by somebody who doesn't really know what it does." **(Diabetologist)**

"Either the cost needs to come down or it needs to be implemented better to show that it can be cost-effective under certain circumstances. Those are both gaps that have not been filled." **(Academic)**

Ultimately, it is a lack of education among GPs, practice nurses and patients that is cited as the principal barrier to the uptake and adoption of medical devices and technologies in the NHS. Some specialists suggested that GPs lack the confidence firstly to identify those patients who would benefit most from these technologies, and secondly to explain how they should be used.

"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)**

Getting ready for future innovation

The research suggests there is ample room within diabetes care for new innovations to support self-management. This might include the use of smartphone technology and apps for patient education and monitoring, for example enabling patients to capture data more easily on their blood glucose, calories consumed and exercise taken, and for this to be easily shared with their medical team, be they GP, dietician or diabetologist.

"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 become part of the working relationship." **(Diabetes specialist nurse)**

"From a patient point of view, there are obviously smartphone applications, the internet etc., so there are other ways for patients to receive their information, although one size doesn't fit all." **(Diabetologist)**

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).[20] 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, both in terms of 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.

Drivers for change

Top findings from ComRes

Respondents were asked what they considered to be the most successful drivers for change in diabetes practice and outcomes.

- **Success of the QOF 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.
- **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.
- ***Action on Diabetes* does not go far enough:** While *Action on Diabetes* is considered a valuable statement of intent and ambition, respondents are looking for more support on the practical implementation of good clinical practice in diabetes.
- **Limited knowledge of available policy levers:** The QOF, NICE guidance 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.

The State of Diabetes Care in the UK, ComRes, September 2014

In defence of the QOF

“I think the QOF’s been great for diabetes, I think it has improved. If you look at QOF data over the years it has improved numbers at least. It hasn’t captured the patient experience, but it has improved [...] the blood pressures and the cholesterol and the number of people taking different medications.” **(Diabetologist)**

Overall, the QOF is perceived to have effectively driven change in clinical practice, particularly among non-specialist HCPs.

There is some agreement that by setting a minimum standard for care, more primary care professionals are conducting the essential basic checks for people with diabetes. Some also suggest that the QOF has not only improved attainment figures, but has also improved outcomes for individual patients.

“The Quality Outcomes Framework has been great for GPs. [...] I do think that it’s definitely improved the standard of care for a lot of patients.” **(Diabetes specialist nurse)**

“I think if you look at the blood pressure and cholesterol in this country, it has definitely come down since QOF started. No question about it. So it is doing what it actually is supposed to be doing: reducing the cardiovascular risk factor. [...] So, from that point of view, you have got to be able to turn around and say ‘That’s very good’.” **(Diabetologist)**

“QOF’s got quite a lot of stick because I think the tabloids managed to break it down into ‘Your doctor gets £7 for asking you if you should think about quitting smoking’, but a lot of the evidence from what I’m told [...] is that actually it’s a fairly reasonable and successful measure.” **(Journalist)**

The fact that this is a financial incentive is perceived to drive behaviour change among clinicians in a way that non-financial guidelines (such as the NICE guidelines) are not able to do.

"Doctors listen to them [financial targets] because money talks, so I think they are very important and have a huge effect on how doctors work. An immediate effect – probably quicker than NICE guidelines." **(Journalist)**

Respondents welcomed the fact that the QOF sets a clear baseline for quality, making clear that no primary care provider should be achieving anything less than this minimum standard. Moreover, having a quantitative and robust measure of quality is said to help to identify those practices that are underperforming.

"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)**

The QOF: a critique

This strong baseline does not mean that the QOF is considered the perfect model. Indeed, while there is a sense that the QOF has had a positive impact overall, there are significant caveats.

Firstly, as it sets a minimum baseline, there is little sense that the QOF drives exceptional practice or innovation.

"I think having the QOF has reduced cholesterol and things like that over the past 10 years dramatically in the UK. […] Having targets and having some kind of financial inducement does work. It drives behavioural change. It may not be the best thing in the world, but it is there." **(NHS manager – commissioner)**

"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)**

Secondly the QOF, by its very nature, measures whether certain processes are carried out, but provides little evidence of any impact on outcomes in the medium to long term. On this there was consensus across all audiences, from healthcare professionals and managers, to policy-makers and commentators.

"[QOF] is very effective at focusing attention on the specific disease areas that are included [but] does it always ask the right questions?" **(Journalist)**

"I think they [QOF measures] are good at improving progress but not necessarily outcomes. We know that they are useful for people having their blood pressure measured and having their HbA1c measured but I don't think there's a huge amount of evidence that they actually help to address those issues." **(NHS manager – commissioner)**

"QOF is an artificial target, designed to incentivise primary care to do something about their patients for money. All it asks is for practitioners to measure, for example, blood glucose, and they then receive 'QOF points' and money. But just measuring or checking something does not make the problem better." **(Diabetologist)**

Finally, specialists in diabetes care say that while the processes and targets laid down by the QOF are relevant in the majority of cases, there still remains a minority of patients who are not best served by the QOF as it currently stands.

"I think QOF has been an excellent experiment but I don't think that it's good for patients in terms of personal care. I think that the drive to get so many of the practice populations below 7.5% or 8.5% ignores some of the personal issues that the patients might have in terms of hypoglycaemia and the agents that you use. So, I'm not convinced that QOF is the best thing for diabetes care. Perhaps from an epidemiological point of view it could be seen as a success." **(Diabetologist)**

"I think that for the majority of patients [QOF] has been a good thing, but for a number of patients it has been exactly the opposite. There has been a regression to achieving the same diabetes control for all, which for many is really good, but for some patients achieving these targets has been a detriment to their health." **(Diabetologist)**

What next for the QOF?

While the majority of respondents are cautiously optimistic about the impact and future of the QOF, there is a vocal minority of detractors.

These are largely non-healthcare professionals who believe that paying healthcare professionals extra for doing things that should be a part of their job, is the wrong strategy to adopt in the pursuit of good outcomes for patients.

"There has been far too much emphasis on QOF and achieving QOF points and QOF income. The profession is really clear that what they want to be able to do is just get paid for looking after patients. A good GP doesn't need the incentive of QOF points to check the blood sugar of a diabetic patient. That's just what good care is. We should hold people accountable for providing good care and be really transparent about whether they are doing it but we shouldn't manage professional people through a series of tick box targets." **(Policy official)**

"Doctors get points for testing and putting people on statins. I think this is wrong and the policy is ridiculous. If I was a doctor, I would get a QOF point for measuring someone, but then not get anything for doing something about it." **(Journalist)**

Others, again in the minority, cite evidence that the QOF does not improve outcomes for patients on the ground, and therefore is ineffective in its current form.

"Regarding QOF – I see it as a tick box exercise. Yes, things get done, but as far as I am aware, the national audit that was published in February time showed that [...] outcomes did not improve. Perhaps it is that people with diabetes are not bothered about their care or how they look after themselves, or maybe GPs don't have the time once they have found the problem, to treat it and improve it. QOF is a financial target – it does not look at clinical targets." **(Diabetes specialist nurse)**

"QOF's a tick box. Any sort of outcome measure needs to be able to really show significant improvement for patients and disease management, and I don't think that the way QOF works currently does that. It becomes a list of things that you've done, not necessarily what you then do with the information. And certainly if you look at the levels of amputation and complications to diabetes, obviously things have not been picked up – so therefore I don't think QOF's as effective as it could be if it was used in a different way." **(Professional body)**

Overall, however, the picture is of an incentive framework that works well to improve standards of care, and while imperfect, it is driving up national standards of care for people with diabetes.

"QOF has come a long way since the beginning, but it's still a rather ineffective mechanism because what it does is count processes rather than outcomes, and only counts them up to the level at which QOF points get paid, so doesn't actually monitor beyond that. [...] Let's not get rid of it, it's better than having nothing; at least we're counting something. The risk at the moment is that QOF will get swept away because the Secretary of State doesn't like it." **(Patient group)**

A future Quality and Outcomes Framework 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. A future QOF should have a direct impact on outcomes and support clinicians to manage their patients better in the long term.

Advice from NICE

"The guidance is absolutely superb. There is tons of good guidance such as SIGN guidance and NICE guidance, it's very well thought out. We have absolutely no shortage of guidance." **(GPwSI)**

"I think NICE and SIGN guidelines are both pretty good." **(Patient group)**

Attitudes towards NICE guidance amongst healthcare professionals are largely positive. It is perceived to be of a high quality, and is trusted by both those treating diabetes on the ground and those shaping NHS policy and strategy.

"We have got NICE guidance for managing type 2 diabetes, type 1 diabetes, pumps, obesity. That's all out there and that's all recognised as top quality advice." **(Diabetologist)**

"I think NICE guidelines are really useful and we've used these NICE guidelines to audit care locally and we've also used NICE guidelines to look at prescribing formularies locally and they have been extremely successful in helping GPs make decisions about type 2 diabetes care and the escalation of care." **(Diabetologist)**

However, some note that NICE can struggle to keep up with the fast pace of change in clinical practice. A number of healthcare professionals noted that new medicines, such as glucose lowering therapies, are not yet covered by existing NICE guidelines, the knock-on effect being the slow uptake of these innovative therapies.

"In terms of glucose lowering, we've got new therapies that cost up to £30–40 per month and one of the things we're waiting for is the NICE organised guidelines of diabetes that are currently up for rewriting and they should all be published in the middle of next year." **(Diabetologist)**

"They're not perfect but as a non-specialist they give you a good start and provide a framework upon which you can build. [But] a lot of new drugs have appeared that are still jostling for position, if you like, as to where they're going to sit, so having an endorsement from NICE would be nice for those agents and non-specialists to know exactly where a new drug fits into the grand scheme of things." **(Diabetologist)**

There is a sense that NICE guidelines can be divorced from the realities of delivering patient care on the ground. The NHS is working with increasingly limited resource, yet is seeing growing numbers of patients, all of whom are living longer with increasingly complex and multiple conditions. While having clear guidance on what best practice looks like is perceived to be valuable, some said it can be somewhat simplistic when considered alongside clinical reality.

"I think they [NICE guidelines] are a useful tool because they show doctors what they should be doing and doctors tend to, in my opinion, over time 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 et cetera." **(Journalist)**

"I think generally their [NICE's] stuff is pretty well received and well researched, thorough and useful to people on the front line. I think that there is definitely an issue about how you go about making research guidelines for people with multiple complications. The combined impact of loads of drugs and lots of medical interventions on somebody with really complicated numerous problems is still something that the NHS and the NICE guidelines hasn't quite adapted to yet." **(Policy official)**

More critically, while guidance from NICE is considered to be of a high standard, there is some doubt as to whether it actually drives change in clinical behaviour. NICE will develop guidance, but ultimately it is not responsible for its implementation. Many respondents felt that there is therefore no clear measure of its impact on clinical practice and outcomes.

"NICE guidance is good, but the problem is that NICE doesn't have a role in implementing its own guidance. NICE is there to set the standards, not to monitor whether they're happening or not, so nobody at the moment really monitors whether they're happening or not." **(Patient group)**

"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)**

There is therefore a belief that more could be done to ensure that NICE guidelines are applicable to the growing complexities of clinical context, that they are implemented on the ground and that they genuinely drive high-quality patient care and outcomes.

Action on Diabetes

In March 2014, NHS England published its plan for diabetes care in England. While the aims and objectives behind ***Action on Diabetes*** are applauded by opinion formers, there is a sense that the plan itself provides nothing new. As a result, it is not regarded as providing a particularly inspirational vision for NHS diabetes care in the future.

"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)**

> *“The policy document has been watered down, reformulated in terms of the new NHS and isn’t as detailed as the stuff in the parent document. It’s been re-written in the new NHS language, in the new domain, in the new NHS-speak.”* **(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)**

As such, despite representing a good first step in setting a vision for diabetes care under the new NHS structure, many believe that *Action on Diabetes* does not go far enough.

Opinion formers and healthcare professionals question whether it offers anything which previous national policy initiatives did not – and therefore, whether it will drive change where previous initiatives have failed. They call upon NHS England to go beyond its series of objectives, and create a plan for practical implementation.

> *“It is the first and only product that NHS England has produced stating what they will do. I think there are some things in it where they are still debating whether they will actually do them or not. In terms of impact on the ground, it has provided the national clinical director with a framework to try to create the environment and galvanise local areas in particular in a strategic clinical network to deliver on quality improvement. However, it does not and it has not and it will not provide a mechanism to improve quality of care delivered by general practices and communication and relationships between primary and specialist care and improve commissioning.”* **(Patient group)**

Respondents also highlighted the capacity challenges facing the diabetes team in NHS England.

> *“All it is, is a list of things NHS England is going to do, which isn’t the same as having a Diabetes Action Plan because it isn’t what other people need to do, so it’s very partial. […] There is only one person in NHS England with diabetes in their title which is bizarre, and he’s only got 2 days a week or 3 days a week or something like that and he’s got no budget and no staff. I would suspect if you went round the country asking the average CCG diabetes lead, they wouldn’t even know it existed.”* **(Patient group)**

Currently, opinion formers are sceptical that *Action on Diabetes* will have a discernible impact on the quality of care delivered on the ground.

Diabetes needs a more detailed national framework and plan for success

Diabetes service design and delivery is currently being led 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. 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.

Educational programmes

A minority of more informed stakeholders – particularly healthcare professionals and those with a personal interest in or experience of diabetes – highlight structured educational programmes as critical levers for driving change in standards of care. DAFNE, DESMOND and X-PERT are all structured educational programmes which are seen to be largely effective in driving improved clinical outcomes.

> *"The Government insisted that all patients diagnosed with type 2 diabetes had a structured education programme delivered. On the whole, in our area most patients – I would say 80% – get a structured education programme delivered to them so that they know what it is [and] what to expect ... And this drives change."* **(Diabetes specialist nurse)**

> *"In terms of the DESMOND Programme and the other educational programmes for diabetes, I think that has been very useful."* **(GPwSI)**

However, healthcare professionals and NHS stakeholders highlighted significant variation in provision. In particular they raise the fact that some cohorts of patients with specialist needs are not well served by any of the national programmes, such as children with diabetes. Where specialist programmes are available, there is not sufficient capacity to meet demand.

> *"There are programmes such as the DAFNE programme, which has been well researched and there's a big evidence base for it, but that's only available in maybe a third of areas. Even in centres where they've got teams trained to deliver DAFNE, they're probably not delivering enough programmes to meet the population that they have with type 1 diabetes."* **(Diabetes specialist nurse)**

> *"Only 30% of patients who should be having the education from the DESMOND programme are getting it."* **(NHS manager – commissioner)**

> *"There are guidelines for education that people are given when they develop diabetes, but not every area of every practice has that."* **(Diabetes specialist nurse)**

Policy stakeholders and opinion formers suggest that this fragmentation stems from the fact that these educational programmes are not centrally driven, and therefore provision necessarily varies.

> *"Type 1s get a type of education called DAFNE. There are a lot of education courses along the same lines. There is also the Diabetes Education Network, which acts as a sort of unofficial watchdog to check that the courses are alright. But the problem with this is that they are all very much individual. It's not a Government organisation, it's run by individual diabetologists and the courses are taught by dieticians and practice nurses. There's just not enough capacity at the moment to educate GPs about who needs educating."* **(Journalist)**

> *"You've got the odd anomalies going on. It's piecemeal really. The government will say 'That's great, you carry on', but no one thought about the things that are being left out here, although it's not that the things that are happening are bad."* **(Journalist)**

> *"I know that Diabetes UK did some work around type 1 diabetes in children and insulin, and so they developed this school charter where the school have to have certain plans for children who are on insulin. This kind of work is important, but I think others can get involved too."*
> **(NHS manager – commissioner)**

More broadly, it is telling that only a small minority of stakeholders are able to name specific education programmes, suggesting that awareness is low, and that such programmes may not be publicised as effectively as they could be. That said, there is a sense that where there is consistent provision, these educational programmes have a significant impact on clinical outcomes for people with diabetes, suggesting that diabetes care could be further improved if they could be more effectively driven on a national level.

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.

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 will likely 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.[21]

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 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 5,000 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 that 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 Quality and Outcomes Framework 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.

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 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 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 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 which 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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COM-0001-02/15