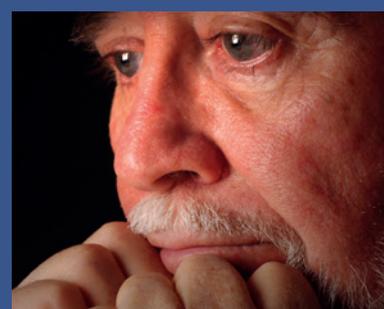
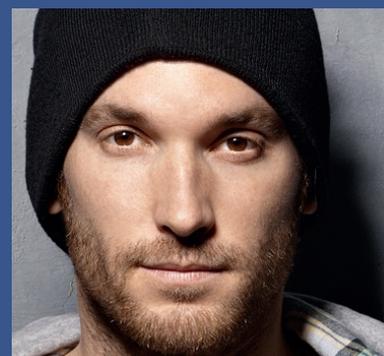




# Diabetes 2015 Care in Crisis

A survey  
**HIGHLIGHTING**  
the views of people  
with diabetes and  
how that relates to  
the reality of today's  
NHS

This report was prepared and funded by the  
Independent Diabetes Trust, a charity for  
people who live with diabetes





# INDEPENDENT DIABETES TRUST

The InDependent Diabetes Trust (IDDT) is a registered charity which offers help, support and information to people with Type 1 and Type 2 diabetes and their families. It differs from many other medical charities in that it is entirely funded by voluntary donations and does not accept funding from the pharmaceutical industry. This enables IDDT to be completely independent and uninfluenced by funding sources.

Note: IDDT is referred to as the Trust throughout this report.

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## Introduction

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**There are over 3 million people with diabetes in the UK with an estimated 90% having Type 2 diabetes and the remaining 10% having Type 1 diabetes. The incidence of both types of diabetes is increasing, especially Type 2 diabetes and by 2030 the number of people with diabetes is expected to rise to 4.6 million.**

Diabetes costs an estimated 10% of the NHS budget, equivalent to £10 billion per year. These high costs are mainly due to treatment of the complications of diabetes which include heart disease, visual impairment and blindness, kidney disease and nerve damage which can lead to amputations. Evidence shows that good control of both Type 1 and Type 2 diabetes reduces the risk of diabetic complications. However, despite improvements in glucose monitoring, insulin administration, new drugs for Type 2 diabetes, studies show that many people with diabetes have what can only be classed as 'poorly controlled' diabetes.

While the Diabetes Prevention Programme is important, the Trust is very concerned that many of the over 3 million people who already have diabetes are not receiving the care and treatment they need and deserve.

The Trust has over 17,000 members, all of whom live with diabetes. It is clear from contact with members that the care, education and treatment of people with diabetes vary greatly across the country. Some people are receiving excellent care but unfortunately for many people, it is less than adequate. As a result of this in January 2015, the Trust circulated a survey to its then membership of 15,569 to investigate their views on the services they receive and their priorities for improving their care and therefore their future health.

Diabetes fits into the NHS category of 'long-term conditions' but the Trust believes this is not appropriate. The Trust recommends that an organisation similar to the now non-existent NHS Diabetes should be reinstated to improve care and the outcomes for people with diabetes. The case for this is covered by examining some of the evidenced-based key issues related to diabetes and those expressed by people with diabetes in the survey carried out by the Trust.

Internationally in June 2015, leaders at the G7 Summit were challenged by the International Diabetes Federation (IDF) to develop and implement effective policy options to improve health outcomes of people with diabetes and to prevent the onset of Type 2 diabetes. The IDF directed the call to action to all prime ministers, ministers of finance and ministers of health of the G7 nations. The Trust's members hope that their views will be listened to by those UK ministers.



## Summary

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### Better care, better outcomes – the needs of people with diabetes

#### The Five Year Forward Review

##### The Trust recommends:

- People who are already living with Type 1 and Type 2 diabetes are recognised as a priority in the Five Year Forward Review, separately from obesity.
- As over 3 million people in the UK have diabetes, diabetes should have its own place within the NHS system in a similar way to dementia, a condition with less than a million people and a third of the number of people with diabetes.
- The now non-existent NHS Diabetes should be reinstated to improve care, the outcomes for people with diabetes and the education of health professionals in order to achieve these aims.

#### Education

##### The Trust recommends:

- Clinical Commissioning Groups (CCGs) should be strongly encouraged to follow NICE guidance to commission convenient and high-quality structured education courses for all those who wish to attend. CCGs should also offer other learning opportunities about diabetes such as peer support, group learning and online courses.
- An estimated 2.5 million people may not have received high quality structured education courses, therefore to alleviate this problem, CCGs should provide basic hard copy information in non-medical language about diet, exercise, the differences between Type 1 and Type 2 diabetes and what medications are designed to do.

#### Dietary Recommendations

- As diet is part of the treatment for both Type 1 and Type 2 diabetes and the present dietary guidelines are over 30 years old, the Trust recommends a review to produce evidence-based dietary guidelines for diabetes and the general public.

cont...





*summary continued*

## The 9 Key Health Checks

- The Trust recommends that resources are increased to improve the care of people with Type 1 and Type 2 diabetes by ensuring that they all receive the 9 key health checks recommended by NICE to prevent diabetes complications and reduce the long-term costs of treating complications.



### Foot Care

#### The Trust recommends:

- Improvement in the knowledge of health professionals in primary care about foot problems and when referral is necessary, by further training.
- Increasing the numbers and availability of NHS podiatrists to provide greater access to people with diabetes and help to reduce the risk of serious foot problems.



### Children and Young People with Type 1 Diabetes

Only 16.1% of children aged 12 years and older are receiving the 7 health checks recommended by NICE and less than half are receiving some form of structured education. Both of these are contributing to too many children with Type 1 diabetes showing early serious long-term complications.

The Trust recommends increasing resources to provide improvements in the care of children and young people with Type 1 diabetes who have to live their whole lives with the condition and therefore are at great risk of diabetic complications.



### Older People with Diabetes in Residential Care

#### As 27% of people in residential care have diabetes, the Trust recommends:

- Good quality training for care home staff of all levels to avoid the health and quality of life of this vulnerable group suffering.
- Full national implementation of the standards recommended in the Diabetes UK 2010 report 'Good clinical practice for care home residents with diabetes.'
- Mandatory demonstration of this as a CQC requirement in a similar way to dementia care.
- CCGs to put plans in place to improve diabetes care for older people resident in care homes.
- The use of the Passport for People with Diabetes in Care Settings prepared jointly by the Trust and the Institute of Diabetes in Older People.

# NHS Five Year Forward Review

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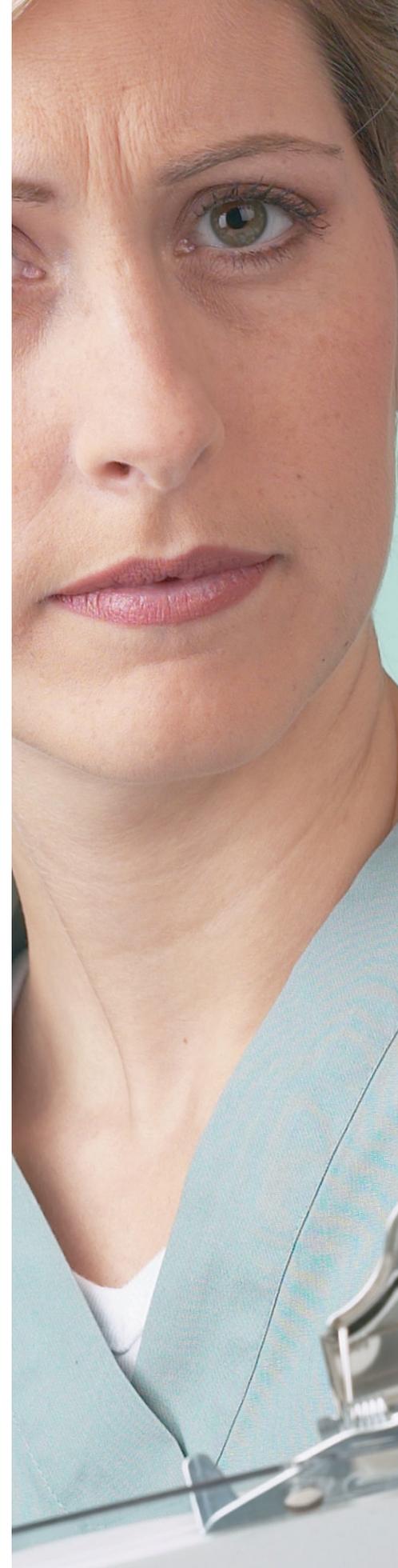
**In March 2015, NHS England published its business plan for 2015/16, NHS Five Year Forward Review<sup>(ref 1)</sup>, setting out ten priorities intended to improve access to services for patients, drive for better value for money and to build the foundations for the future health and care system.**

Diabetes is fourth on the list of the ten priorities but only as 'Obesity and preventing diabetes' which is a public health issue. While accepting preventing diabetes should be a priority, this link with obesity can only apply to some people with Type 2 diabetes and not Type 1 diabetes, as this cannot be prevented.

The Trust is concerned that more than 3 million people who are already living with Type 1 and Type 2 diabetes are not seen as a priority in the Five Year Forward Review, especially as the care in many areas is not good enough as shown by the following two examples.

- A new analysis of World Health Organisation data led by Professor Russell Viner at the Institute of Child Health,<sup>(ref 2)</sup> has shown that the UK has a high and rising mortality rate among young people with Type 1 diabetes between the ages of 15 and 24 years compared to other EU countries. The study did not examine the reasons for the high mortality in this age group but considering that only 16% of children and young people receive the essential 7 annual health checks in the UK, it is unsurprising that they are at risk of increased mortality and the development of complications later in life.
- A recent analysis of people with Type 2 diabetes by Diabetes UK<sup>(ref 3)</sup> shows that only about a fifth of people diagnosed with Type 2 diabetes during the last four years have their condition under control. Based on National Diabetes Audit, 2012-13 data<sup>(ref 4)</sup>, the analysis shows that just 22.4% of those who have had Type 2 diabetes for up to four years, estimated to be 1 million people, meet the recommended levels for blood glucose, cholesterol and blood pressure. People not meeting the recommended levels are at increased risk of future complications such as retinopathy, kidney failure, neuropathy and amputation. This highlights the importance of giving people with Type 2 diabetes the support they need as soon as they are diagnosed but presently just 14% of people with Type 2 are offered diabetes education soon after being diagnosed.

The Trust recommends that people who are already living with Type 1 and Type 2 diabetes are recognised as a priority in the Five Year Forward Review, separately from obesity.



# Education

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In the Trust's survey, over 90% of people felt that an education programme at the time of diagnosis or 6 months after would be either helpful or very helpful. This finding supports the NICE Diabetes in Adults Quality Standard 2011<sup>(ref 5)</sup> recommendations that people with diabetes, and/or their carers should receive a structured education programme which should fulfil the nationally agreed criteria from the time of diagnosis, with annual review and access to ongoing education. NHS England is statutorily required to have regard to this.

## Education courses

There are a number of national and locally developed patient education programmes available:

- Dose Adjustment For Normal Eating (DAFNE) for Type 1 diabetes.
- Diabetes Education and Self-management for Ongoing and Newly Diagnosed (DESMOND) for Type 2 diabetes.
- A range of tools and guidance to help local services choose the best programmes to meet the needs of their local population is also available, for example the web based Transforming Participation in Health and Care tool.
- Some areas develop their own programmes.

However, using the figures from the National Diabetes Audit 2012 - 2013<sup>(ref 4)</sup> only around 4% of people newly diagnosed with Type 1 and 17% of those with Type 2 diabetes were offered a structured education programme. In addition, the All Party Parliamentary Group for Diabetes Report, 2010-15<sup>(ref 6)</sup> highlights that of the newly diagnosed people offered access to a formal diabetes education course, only 3% actually attended one. The report also showed a lack of ongoing support after diagnosis, such as refresher courses and self-help groups.

This report showed that the key barriers to people receiving education and support are:

- Clinical Commissioning Groups (CCGs) are not commissioning formal education courses.
- Even when formal education courses are offered, they do not always meet the needs of people with diabetes, for example many are held during work times.

- Some healthcare professionals do not recognise the importance of education programmes and so do not promote them to patients.

The All Party Group made the following recommendations which the Trust supports:

- CCGs commission convenient and high-quality structured education courses and offer top-up courses for all who wish to attend.
- CCGs offer other learning opportunities about diabetes and support through peer groups, 'taster sessions', online courses and communities.

The NHS Five Year Forward Review<sup>(ref 1)</sup> also commits the NHS to investing in 'group-based education and peer-to-peer support for people with long-term conditions'. It remains to be seen, how, when and where these will take place for people with diabetes.

## The Trust proposes that people are offered basic information at diagnosis

The widely used figures for the numbers of people with diabetes is over 3 million, so using figures from the National Diabetes Audit, many thousands of people with diabetes have not received the recommended structured education programme. Whether structured education is offered in groups or to individuals, the Trust questions the logistics of whether it is possible to rectify this situation for people already diagnosed with diabetes.

- Where are the resources to come from to offer structured education to 2.5 million people, in addition to those being newly diagnosed?
- Are GP practices able to take on this increased workload and do they have sufficient qualified staff to take on this responsibility?
- How can CCGs be encouraged to commission formal education courses when many of them have failed to do so since their formation?

## The Trust's Proposal for Education

The evidence from our survey and the anecdotal evidence that IDDT receives from people newly diagnosed, especially those with Type 2 diabetes, is that many of them receive little or even no useful information at diagnosis.

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**The Trust recommends:**

- (i) CCGs commission convenient and high-quality structured education courses and offer top-up courses for all those who wish to attend.
- (ii) CCGs offer other learning opportunities about diabetes, peer support, group learning and online courses.
- (iii) CCGs should start by providing hard copy information about diet, exercise, the differences between Type 1 and Type 2 diabetes and what medications are designed to do, in non-medical language. This would help to alleviate the logistics of the newly diagnosed and 250,000 people not having received a structured education programme and would give people immediate access to basic information which would help them to:
  - understand their type of diabetes,
  - the necessary lifestyle changes,
  - the management of their diabetes,
  - prevent unnecessary anxiety through lack of information,
  - reduce the risk of complications.

**Suggested publications for inclusion in an Information Pack**

Understanding Your Diabetes

Diabetes Everyday Eating

Type 2 Diabetes – management and medication or Type 1 Diabetes – know the facts

Diabetes and Exercise

**Note:** IDDT already supplies all these booklets, and others, in bulk to many practice and specialist nurses across the UK to give to their patients.





The dietary recommendations of low fat / high carbohydrate advised for the last 30 years are not, and never were, based on evidence. The Trust has argued that the low fat, high carb diets simply do not make sense, especially for people with diabetes. If more carbohydrates are consumed than needed for the energy used, then the excess carbohydrates will increase weight in the general population and in people with diabetes. In people with Type 1 diabetes this results in the need for higher insulin doses (which also increases weight and cost) and a greater risk of hypoglycaemia. In people with Type 2 diabetes, greater weight means more medication is necessary.

### **Understanding why the guidelines were introduced**

The present dietary guidelines were introduced in 1977 by the US government and in 1983 by the UK government. The Trust fully understands their introduction aimed to reduce coronary heart disease (CHD) by reducing fat intake and increasing the carbohydrates to replace the fats. However, it is surprising that something as important and far reaching as national diets in leading countries can be introduced without supporting evidence that (i) they do what they are supposed to and reduce CHD and (ii) without investigating the possible consequences of the proposed guidelines. Up to now, no analysis of these guidelines has ever been undertaken.

A new review (Open Heart, BMJ, Feb 9 2015<sup>(ref 7)</sup>) examined evidence from randomised controlled trials available to the US and UK regulatory committees in 1983 when they made their decisions to implement the new guidelines. The trials looked at the relationship between dietary fat, cholesterol levels and the development of cardiovascular disease.

There were a total of 2,467 male participants in 6 dietary trials, the intervention group was given the low fat / high carb diet and the control group ate a normal diet. The results showed:

- There were 207 and 216 deaths from cardiovascular disease in the intervention group and control group respectively, so little difference.
- There were no differences in all-cause mortality and non-significant differences in CHD mortality resulting from the dietary interventions.
- The reduction in cholesterol levels was significantly higher in the intervention groups but, importantly, this did not result in significant difference in CHD or all cause mortality.

# Dietary Recommendations

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The researchers could only conclude that government dietary fat recommendations were untested in any trial before being introduced and without any supporting evidence from randomised controlled trials.

An American review of the best documented and least controversial studies was published at a similar time as the above BMJ review. It is very outspoken about the dietary guidelines and makes the following statement.

 *The current state of diabetes care in the US health system shows the inability of existing recommendations to control the epidemic of diabetes, the failure of low fat diets to improve obesity rates, cardiovascular risk or general health and continual reports of serious side effects of commonly prescribed diabetic medications. The immediate benefits of carbohydrate restriction in diabetes patients include reduction of high blood glucose, less requirement for weight loss, fewer side effects than medication therapy and the reduction or elimination of medications (in Type 2 diabetes). The current evidence supports the use of low-carbohydrate diets as the first approach to treating Type 2 diabetes and is an effective adjunct to pharmacology in Type 1.* 

Information from the National Health and Nutrition Examination Surveys<sup>(ref 8)</sup> indicates a large increase in carbohydrates as a main contributor to excess calories in the US from 1974-2000. Carbohydrate intake in men rose from 42% to 49% and in women from 45% to 52%. There is information to suggest a link between increased carbohydrate consumption and increased diagnoses of Type 2 diabetes.

An editorial in the British Journal of Sports Medicine, 22nd April 2015<sup>(ref 9)</sup> by researchers from the UK, South Africa and Australia says that cutting carbohydrate intake should be the primary strategy for treating diabetes as it is the single most effective approach for reducing all features of the metabolic syndrome.

They also say that the benefits of cutting out foods like crisps, chips, cakes and sugary drinks occur even in the absence of weight loss. The prevalence of Type 2 diabetes increases 11-fold for every 150 additional sugar calories consumed daily compared to the equivalent amount of calories consumed as fat. They also point out that sugar calories promote fat storage and hunger but fat calories induce the feeling of fullness.

The editorial was highly critical of public health messages for being 'unhelpfully focussed' on maintaining a healthy weight through calorie counting rather than the source of the calories, which is the important factor. It also points out that our calorie-laden diets now generate more ill health than physical inactivity, alcohol and smoking combined.

The evidence now suggests that up to 40% of those within normal weight range will still have some of the harmful metabolic abnormalities typically associated with obesity.

The Trust recognises that it would be wrong to suggest that the increase and link between obesity, overweight and Type 2 diabetes is totally due to the high carb/low fat diet. Many other factors have changed over the last 30 years – more sedentary lifestyles, using cars instead of walking, increased use of processed food and sugar-laden drinks. However, these changes only serve to emphasise the need for Public Health England and NHS IQ, the department responsible for diabetes, to update the dietary recommendations for the general public and for people with diabetes and to ensure that such recommendations are based on evidence.

As diet is part of the treatment for both Type 1 and Type 2 diabetes and the present dietary guidelines are over 30 years old, the Trust recommends a review to produce evidence-based dietary guidelines for diabetes and the general public.



# The 9 key health checks

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**The Trust's survey showed that having all the necessary health checks was second in importance to education programmes and the evidence supports this finding.**

On January 14th 2015, Diabetes UK published its annual State of the Nation Report<sup>(ref 10)</sup> with a press release which led with '*The poor state of diabetes healthcare in England is leading to avoidable deaths and record rates of complications.*'

The report highlights statistics from published surveys and audits already mentioned, showing that there has been very little overall improvement in diabetes healthcare during the past year. It highlights that 40% of people with diabetes are not receiving the 9 key health checks recommended by NICE and that some aspects of care are worse, for example, the number of people with Type 1 diabetes receiving the 9 key checks has dropped from 43% to 41%.

Over the last few years, the care of people with diabetes has largely been moved from secondary care to primary care and at the same time, there has been a large rise in the number of people diagnosed, especially with Type 2 diabetes. However, the Trust holds the view that the resources to deal with these changes have not been allocated to GP practices in terms of their staffing levels, diabetes education of the health professionals involved or the necessary funding. There is also a shortage of dietitians and podiatrists to advise and treat the increasing numbers of people with diabetes.

Therefore the Trust recommends that resources in primary care are increased to improve the care of people with Type 1 and Type 2 diabetes, to prevent diabetes complications and reduce the long-term costs of treating complications.

# Foot care



It is recommended that people with diabetes visually inspect their feet daily because they may have neuropathy and a loss of sensation, so relying on symptoms is not sufficient to detect any problems. People need to be informed of this at diagnosis. In addition, according to NICE Guidelines<sup>(ref 11)</sup>, people with active/acute diabetic foot disease should be referred up to the hospital-based multidisciplinary diabetic foot teams and seen within 24 hours of referral.

A study of foot care by Leicester University<sup>(ref 12)</sup> has highlighted the importance of seeking early medical care for people with diabetes with foot problems. The researchers looked at 20 cases of foot problems where care had been delayed by 18 weeks and in one case the delay was 36 weeks. In 30% of the cases where the delay occurred, amputation was needed to prevent even more serious complications. Foot problems are defined as any change in the foot including grazes, wounds burns, dry skin, bunions and ingrown toenails. While these may seem fairly trivial, for people with diabetes they are not - they need early treatment.

The Trust is aware of the new National Diabetes Foot Care Audit which aims to establish the extent to which national guidelines on the management of diabetic foot disease are being met. The audit also aims to provide local teams with the evidence needed to tackle any identified differences in practice which will lead in turn to an overall improvement in management and outcomes but the results will not be available until March 2016, followed by an unknown time for implementation of any recommendations for improvements.

## **In May 2014, Jane Ellison, the Minister responsible for diabetes, made the following answer to a Parliamentary Question**

**“** *The National Institute for Health and Care Excellence (NICE) has published clinical guidance and quality standards on the treatment of diabetes and its complications.*

*The NICE Diabetes Quality Standard is clear that people with diabetes who are at risk of foot ulceration should receive regular reviews by a foot protection team in accordance with its clinical guidance. The Health and Social Care Act (2012) places a duty on NHS England to have regard to the NICE Quality Standards. Clinical commissioning groups (CCGs) should also have regard to them in planning and delivering services, as part of a general duty to secure a continuous improvement in quality.* **”**

She also pointed out that GPs are paid for annually assessing nerve damage and poor blood supply to the feet in people with diabetes.

## **Foot care for people with diabetes is not good enough**

In December 2013, figures from the Yorkshire and Humber Public Health Intelligence Diabetes Footcare Activity Profiles<sup>(ref 13)</sup> showed that people with diabetes in some areas of England were twice as likely to undergo diabetes-related amputations as the national average – as many as 4.9 amputations each year for every 1,000 people with diabetes, compared to the average of 2.6 per 1,000.

A year later in December 2014, Diabetes UK conducted an online survey of 6,696 people with diabetes.

- 32% were not informed about their risk levels at their annual foot check.
- 32% also said they were not given adequate advice about foot care.
- 18% did not have their feet checked for corns, calluses and changes in shape.

According to an analysis of NHS data by Diabetes UK (April 27, 2015)<sup>(ref 14)</sup>, an estimated 414,784 people with diabetes in England are not having an annual foot check, 27.7% of people with Type 1 diabetes and 13.3% of people with Type 2 diabetes. This can lead to serious foot problems, such as ulcers, which in turn can lead to amputation. More than 100 diabetes-related amputations are carried out in the UK every week, and it is estimated that up to 80% of them could be prevented. Amputations and foot ulcers have a huge detrimental impact on quality of life and up to 80% of people with diabetes die within five years after an amputation. Foot ulcers and amputations are also very costly to the NHS and social services. The annual foot check is an opportunity to detect potential problems and take preventative action.

Anecdotal reports provided to the Trust suggest that people are experiencing difficulties in actually acquiring an appointment with an NHS podiatrist, so just making people aware of the need to look after their feet is not sufficient. The Trust recommends

- improvement in the knowledge of health professionals in primary care about foot problems and when referral is necessary,
- increasing the numbers and availability of NHS podiatrists to provide greater access to people with diabetes, to help to reduce the risk of serious foot problems and to meet the NICE guidelines.

# Children and Young People with Type 1 Diabetes

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**In addition to the World Health data in the Introduction, too many children and young people with diabetes are not getting the care they need.**

## **The 7 annual health checks**

The National Paediatric Audit report by the Royal College of Paediatrics and Child Health, March 2015<sup>(ref 15)</sup>, has shown that in England and Wales only 16.1% of young people aged

12 years and older are receiving the 7 annual checks that every child with diabetes should have. While this is a slight improvement from the last audit, it is still very worrying.

The report states that not having the 7 health checks leaves many children and their families missing out on the chance to prevent health problems and this combined with a lack of diabetes education, is contributing to too many children showing early signs of serious long-term complications.

- Over 25% of children with Type 1 diabetes aged 12 and over, have blood pressure above their target.
- Over 7% have early signs of kidney damage.
- Over 14% are already experiencing problems with their eyes, blurred or partial loss of vision, which is particularly alarming.

The report points out that there are considerable variations across the country in completion of the 7 care processes, treatment targets and complications which are primarily the responsibility of paediatric diabetes units.

In addition to the 7 care processes, the recommended screening for thyroid and coeliac disease is only achieved in about half of children with diabetes. There are similar findings for psychological reviews which help to avoid the development depression, eating disorders and other difficulties young people can experience.

## **Education Programmes for Children and Young People**

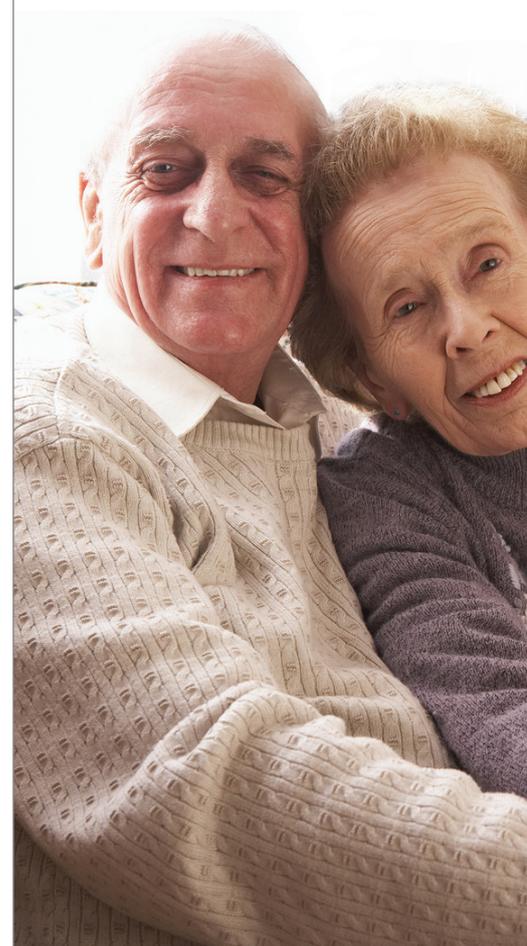
Although NICE recommends age-appropriate structured education programmes for the on-going management of children and young people with diabetes, currently there is no nationally agreed programme. The last National Audit shows that only 45.2% of children and young people are receiving some form of structured education annually but this varies from 11.1% in the South West to 62.0% in the North West. It is clear that there is a great need for better access to structured education for children and young people with Type 1 diabetes.

The Trust calls for a nationally agreed education programme for children and young people to ensure improvements in the care of children with diabetes who have to live their whole lives with the condition and therefore are at great risk of diabetic complications.

# Older people with diabetes in residential care

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**England's first Care Home Diabetes Audit (June 2013)<sup>(ref 16)</sup> has shown that an estimated 27% of residents have diabetes (over 37,000 people). The audit, carried out by the then Institute of Diabetes for Older People (IDOP) highlighted a lack of diabetes-specific policies and procedures. It also shows that through no fault of their own, there were too many untrained staff and ineffective links with NHS services, such as foot care teams.**



## Key findings of the Audit

- Over a third (35.17%) of residents do not know about signs and symptoms of hypoglycaemia, which is when blood glucose levels fall dangerously low.
- 17% of homes had no system in place to check whether those who self-medicate had taken their medication.
- 36.7% homes had no policy for screening Type 2 diabetes – this means that patients could be admitted to, or living in, a care home with undiagnosed diabetes.
- Nearly two thirds (63.2%) of homes had no designated staff member with responsibility for diabetes management.

Clearly too many older and vulnerable people are being denied basic standards of care. With the rise in longevity and the increase in Type 2 diabetes, this situation will only become worse unless urgent action is taken.

## The Trust recommends:

- Good quality training for care home staff of all levels to avoid the health and quality of life of this vulnerable group suffering.
- Full national implementation of the standards recommended in the Diabetes UK 2010 report 'Good clinical practice for care home residents with diabetes'.
- Mandatory demonstration of the above as a CQC requirement in a similar way to dementia care.
- Clinical commissioning groups to put plans in place to improve diabetes care for older people resident in care homes
- The use of the Passport for People with Diabetes in Care Settings prepared jointly by the Trust and IDOP.

# References

1. NHS England (2015) *Building the NHS of the Five Year Forward View*. [online] Available from: <http://www.england.nhs.uk/wp-content/uploads/2015/03/business-plan-mar15.pdf> [Accessed 15/06/15].
2. Viner, R M., Hargreaves, D., Coffey, C., Patton, G C. and Wolfe, I. (2014) Deaths in young people aged 0–24 years in the UK compared with the EU15+ countries, 1970–2008: analysis of the WHO Mortality Database. *The Lancet*. **384**, (9946). pp.880–892.
3. Diabetes UK (2014) *Just one in five recently diagnosed with Type 2 diabetes have it under control*. [online] Available from: [https://www.diabetes.org.uk/About\\_us/News/Just-one-in-five-recently-diagnosed-with-Type-2-diabetes-have-it-under-control/](https://www.diabetes.org.uk/About_us/News/Just-one-in-five-recently-diagnosed-with-Type-2-diabetes-have-it-under-control/) [Accessed 15/06/15].
4. NICE (2011) *Diabetes in adult's quality standard*. [online] Available from: <http://www.nice.org.uk/guidance/qs6/resources/guidance-diabetes-in-adults-quality-standard-pdf> [Accessed 15/06/15].
5. HSCIC (2014) *National Diabetes Audit 2012-2013 - Report 1: Care Processes and Treatment Targets*. [online] Available from: <http://www.hscic.gov.uk/catalogue/PUB14972/nda-audi-ccg-eng-enf-12-13-rep1.pdf> [Accessed 15/06/15].
6. All-party Parliamentary Group for Diabetes (2015) *Taking Control: Supporting people to self-manage their diabetes*. [Online] Available from: [https://www.jdrf.org.uk/downloads/Public\\_Affairs/APPG\\_Diabetes\\_Report\\_-\\_Final\\_Report.pdf](https://www.jdrf.org.uk/downloads/Public_Affairs/APPG_Diabetes_Report_-_Final_Report.pdf) [Accessed 15/06/15].
7. Evidence from randomised controlled trials did not support the introduction of dietary fat guidelines in 1977 and 1983: a systematic review and meta-analysis. Harcombe, Z., Baker, JS., Cooper, SM., Davies, B., Sculthorpe, N., DiNicolantonio, JJ. and Grace, F. (2015) *OpenHeart*. [Online]. **2**, (1) pp.1-7. Available from: <http://openheart.bmj.com/content/2/1/e000196.full.pdf+html> [Accessed 15/06/15]
8. Dietary carbohydrate restriction as the first approach in diabetes management: Critical review and evidence base. Feinman RD, Pogozelski WK, Astrup A, et al. (2015) *Nutrition*. **31**, (1) pp.1-13.
9. It is time to bust the myth of physical inactivity and obesity: you cannot outrun a bad diet. Malhotra, A., Noakes, T. and Phinney, S. (2015) *BJSM*. [Online] Available from: <http://bjsm.bmj.com/content/early/2015/05/07/bjsports-2015-094911.full> [Accessed 15/06/15]
10. Diabetes UK (2015) *State of the Nation*. [Online] Available from: <https://www.diabetes.org.uk/Documents/About%20Us/What%20we%20say/State%20of%20the%20nation%202014.pdf> [Accessed 15/06/15]
11. NICE (2011) *Diabetic foot problems: Inpatient management of diabetic foot problems*. [Online] Available from: <https://www.nice.org.uk/guidance/cg119/chapter/1-Guidance> [Accessed 15/06/15]
12. Diabetes UK (2013) *Putting Feet First campaign highlights areas with high diabetes-related amputation rates*. [Online] Available from: [https://www.diabetes.org.uk/About\\_us/News\\_Landing\\_Page/Putting-Feet-First-campaign-highlights-areas-with-high-diabetes-related-amputation-rates/](https://www.diabetes.org.uk/About_us/News_Landing_Page/Putting-Feet-First-campaign-highlights-areas-with-high-diabetes-related-amputation-rates/) [Accessed 17/06/15]
13. Diabetes UK (2014) *Footcare Survey Results*. [Online] Available from: [https://www.diabetes.org.uk/About\\_us/News/Poor-diabetes-foot-checks/Footcare-survey-results/](https://www.diabetes.org.uk/About_us/News/Poor-diabetes-foot-checks/Footcare-survey-results/) [Accessed 17/06/15]
14. Diabetes UK (2015) *More than 400,000 people with diabetes not getting their annual foot check*. [Online] Available from: [https://www.diabetes.org.uk/About\\_us/News/Too-many-people-not-getting-foot-checks/](https://www.diabetes.org.uk/About_us/News/Too-many-people-not-getting-foot-checks/) [Accessed 17/06/15]
15. RCPCH (2015) *National Paediatric Diabetes Audit Report 2013-2014* [Online] Available from: <http://www.rcpch.ac.uk/system/files/protected/page/NPDA%202012-13%20Core%20Report%202nd%20FINAL%20v%203.3.pdf> [Accessed 17/06/15]
16. IDOP (2014) *England-wide Care Home Diabetes Audit* [Online] Available from: [http://www.diabetologists-abcd.org.uk/Audits/Care\\_Home\\_Diabetes\\_Audit.pdf](http://www.diabetologists-abcd.org.uk/Audits/Care_Home_Diabetes_Audit.pdf) [Accessed 17/06/15]

# Summary report

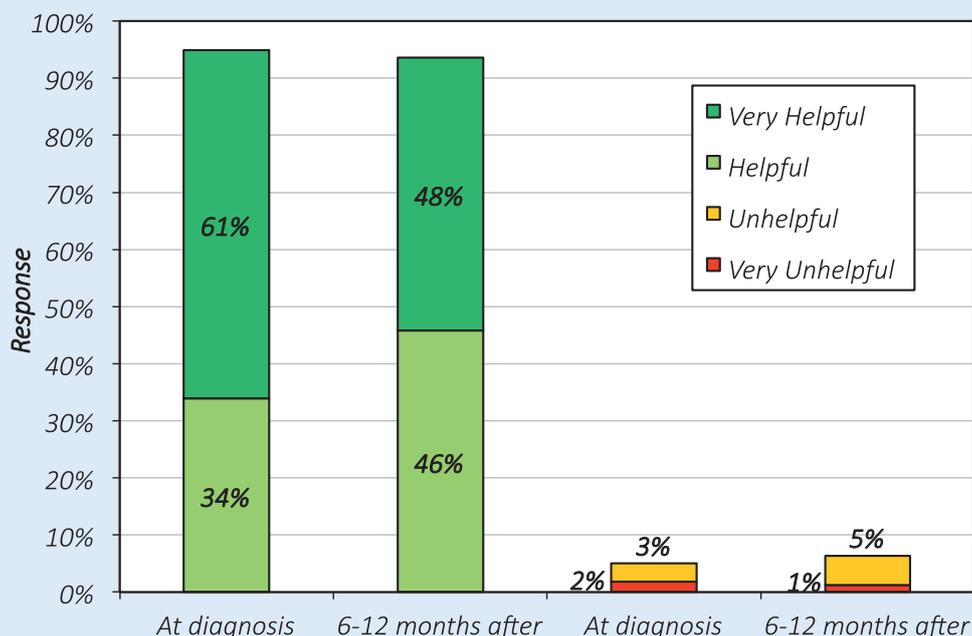
## IDDT questionnaire

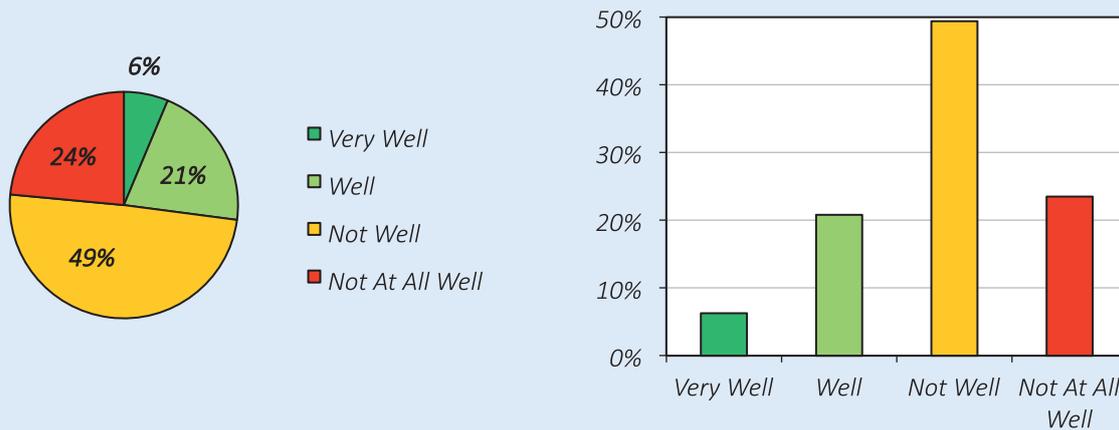
Figure 1 shows responses to question 1 regarding the services offered by the NHS to the patients. We provide both a pie chart and histogram of responses. Over half (55%) of respondents thought the service was better than five years ago, but a large proportion (38%) thought it was worse. 7% thought it was the same, suggesting that patients are polarised about whether the service has improved or not.



**FIGURE 1: Question 1 – “Are the services offered to you by the NHS better or worse than five years ago?”**

Responses to questions 2 and 3 are shown in Figure 2 about how helpful a structured educational programme would have been. 95% of respondents answered either Helpful or Very Helpful at the time of diagnosis, dropping slightly to 94% for a program 6-12 months after diagnosis. The ratio of (Very Helpful):(Helpful) changed from 1.79 to 1.04 depending on whether to introduce a programme at diagnosis or 6-12 months after. Despite this difference, there is little difference between the responses of these two questions - the response is overwhelmingly in support of structured education programme/s at the time of diagnosis and/or 6-12 months after diagnosis. The question of which the patient would prefer was not asked, but the results suggest a preference for at diagnosis.

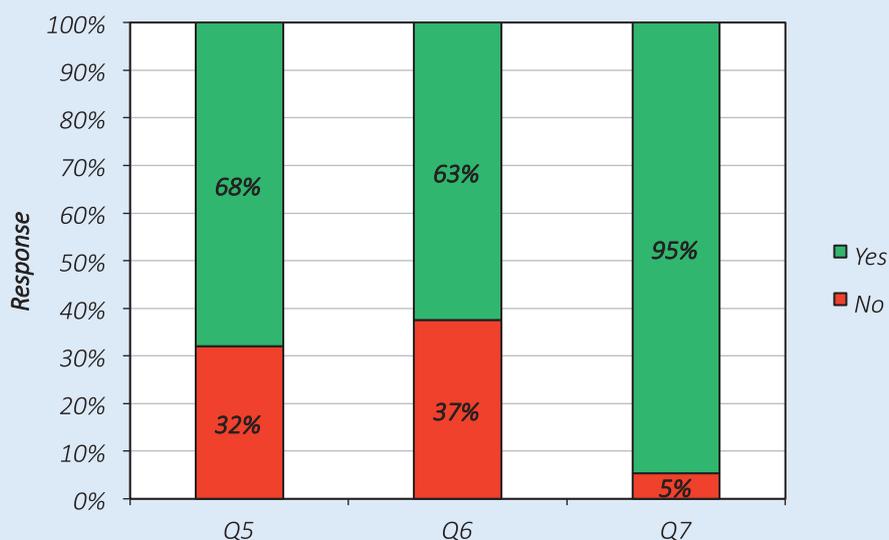




**FIGURE 2: Questions 2 and 3 – “How helpful do you think that being able to attend a structured education programme at the time of diagnosis/6-12 months after diagnosis would have been?”**

**FIGURE 3: Question 4 – “How well do you understand the changes that have been made to the structure of the NHS in relation to your diabetes care?”**

Figure 3 shows responses to question 4 on the level of understanding by patients of changes to the NHS structure related to their diabetes care. Responses have been summarised in both a pie chart and histogram. A high proportion of respondents reported that they did not understand the changes (49% Not Well, 24% Not Well At All, 73% in total). Only 6% said they understood the changes very well.



**FIGURE 4: Questions 5, 6 and 7.**

Figure 4 shows responses to three yes/no questions.

Question 5 – “Do you feel your GP and/or Practice Nurse know enough about diabetes/your diabetes?”

Question 6 – “Were you given appropriate advice and information about diet and exercise at the time of diagnosis?”

Question 7 – “Is your diabetes care reviewed on a regular basis (at least annually)?”

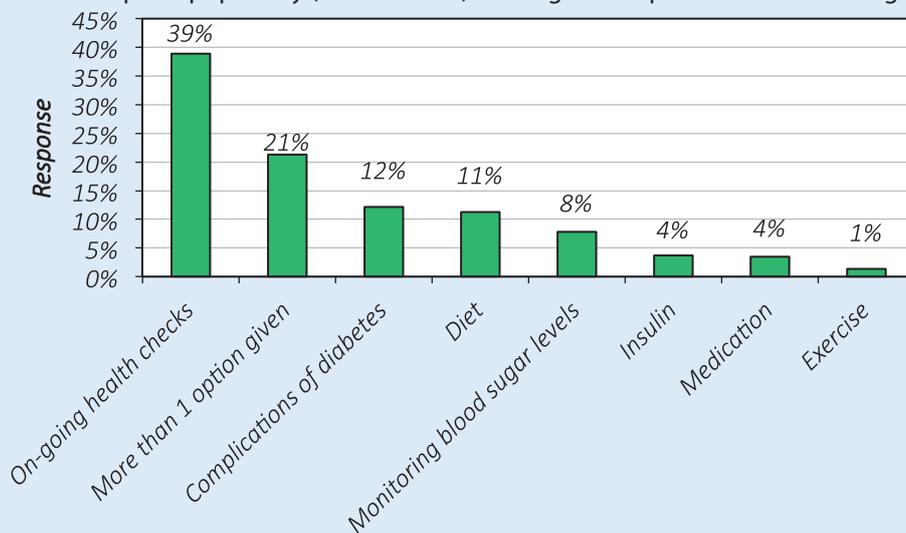
Responses showed that 95% of patients are reviewing their diabetes regularly with their GP/practice nurse according to Question 7 however, in Question 5, 32% did not feel that their healthcare professional knew enough about their diabetes.

Only 63% of patients that responded to Question 6 said that they were given enough information about diet and exercise at the time of their diagnosis, which explains the high proportion of support for the structured education programme covered in Questions 2 and 3.

**FIGURE 5: Question 8 – “Please let us know, from the following options, what is the single most important thing you would like from the NHS, in relation to your diabetes care.”**

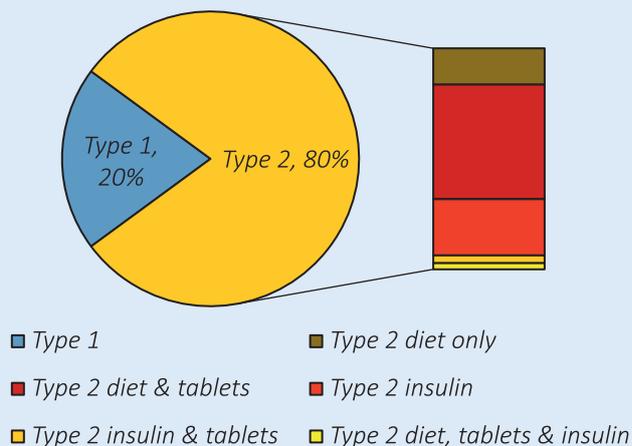
For Question 8, patients were asked what the single most important function from the NHS was, in relation to their condition. Results are presented in order of option popularity (most to least). The highest response was monitoring/on-going health checks which received 39% of responses and 49% of single-answer responses. The least answered option was exercise at 1%.

A high proportion – 21% - responded that no single option was important. This is either an artefact of patients not reading the question properly, or feeling that multiple options were equally important.

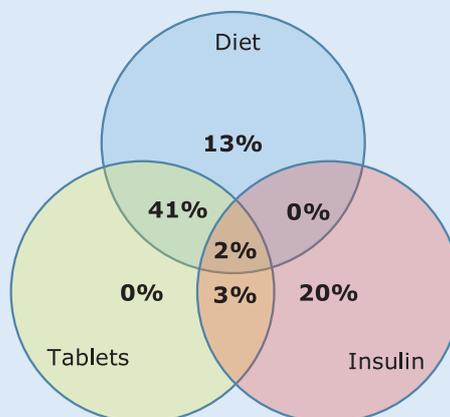


**FIGURE 6a: Question 9 – “Which type of diabetes do you have?”**

Figure 6a shows an expanded pie chart of demographics of responding patients. 20% had Type 1 diabetes (T1) and 80% were Type 2 (T2). Figure 6b expands on the T2 demographics with a Venn diagram of treatment options of which the percentages shown add up to 80%. Most T2 patients were on a combination of Diet and Tablet treatments – 52% of T2 patients. 25% of T2 patients were on Insulin alone. **No respondents reported to only use Tablets or a combination of Diet and Insulin.**



**FIGURE 6b: Question 9 breakdown of type 2 respondents. Percentages sum to 80%, representing 80% of type 2 respondents.**







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*A charity supporting and listening to people who live with diabetes*