ADVOCACY PACK

AVAILABILITY OF BLOOD GLUCOSE TEST STRIPS

This pack has been produced for people with diabetes who are concerned about the restriction of blood glucose test strips on prescription.

It contains information about how to challenge decisions to restrict test strips on prescription.

DIABETES UK

CARE. CONNECT. CAMPAIGN.

Contents

Reviewed June 2013, next review June 2014

Introduction

Diabetes UK has been contacted by many people with diabetes who have been refused prescription of blood glucose test strips or have had their prescription reduced.

The decision to reduce your test strips may have been taken as a cost saving exercise by your local healthcare provider, ie your Clinical Commissioning Group (CCG) in England, Health Boards in Scotland and Wales, or Health and Social Care Trust in Northern Ireland.

What does Diabetes UK think about the restriction of blood test strips?

Over the last two decades it has been firmly established that tight *glycaemic control* is associated with a significant reduction in serious long term diabetes related complications. Self-monitoring of blood glucose is an effective tool in the self-management of glucose levels in people with Type 1 diabetes, and people with Type 2 diabetes using insulin therapy. It helps people with diabetes using insulin achieve tight glycaemic control[1], and to identify low blood glucose levels before the development of severe hypoglycaemia.

In people with Type 1 diabetes there is clear evidence that self-monitoring of blood glucose, together with a range of interventions, improves long term glycaemic control[2]. It is widely recognised that self-monitoring of blood glucose is beneficial, when supported by education, for all people with Type 1 diabetes. As a recent letter from the Department of Health to GPs, commissioners and pharmacists[3] re-emphasised:

> *Their lives depend on insulin injection or pump treatment. They carry out self-blood glucose measurement (SBGM) on finger-prick tests to adjust their insulin dosage according to food, exercise, and other daily events. SBGM is essential for safety checks when feeling unwell, or in situations when the blood glucose might fall too low or too high… In summary, it is essential that people with Type 1 diabetes are prescribed sufficient SBGM testing strips for their clinical needs... This enables people with diabetes to self manage, including understanding 'sick day rules', recognising the symptoms of DKA, early action and how to seek help, and any specific considerations in light of any job they may carry out, especially if it involves driving.*

Whilst the exact role of self-monitoring of blood glucose for people with Type 2 diabetes who are not on insulin is less clear, many people with Type 2 diabetes, and many of the healthcare professionals that support them, recognise that self-monitoring empowers people to self-manage their diabetes and that there are significant quality of life and patient satisfaction benefits. Diabetes UK has recently stated that self-monitoring of blood glucose levels should be available to people receiving sulphonylurea and prandial glucose regulators because of the risk of hypoglycaemia in these groups. Access to self-monitoring for others with Type 2 diabetes should be based on an individual assessment, whereby all options are explored in a joint decision making process between the person with diabetes and their clinician to ensure that resources are adequately used.

Diabetes UK position statements

See page 7 for the position statement for Type 1 diabetes, or page 10 for the position statement for Type 2 diabetes. They can also be downloaded from the Diabetes UK website, or requested from the Diabetes UK Careline on **0845 120 2960**.

Links to position statements:

www.diabetes.org.uk/About_us/Position-statements--recommendations/Position-statements/Self-monitoring-of-blood-glucose-levels-2012

www.diabetes.org.uk/About_us/Position-statements--recommendations/Position-statements/Self-monitoring-of-blood-glucose-levels-for-adults-with-Type-2-diabetes-April-2013

1. Diabetes Control and Complications Trial Research Group: The effect of intensive treatment of diabetes on the development and progression of long term complications in insulin dependent diabetes. N Eng J med. 1993:329:977-986
2. NICE. Type 1 diabetes: diagnosis and management of Type 1 diabetes in adults. Clinical guideline 15.
3. www.gov.uk/government/uploads/system/uploads/attachment_data/file/141448/Safe-care-of-people-with-type-1-diabetes.pdf.pdf

Department of Health Letter

The Department of Health has released guidance on the provision of test strips for people with Type 1 diabetes in England.

This recognises that self-monitoring of blood glucose is essential for people with Type 1 diabetes in order to carry out their daily lives. You can send this letter to your GP, hospital doctor, community pharmacist, Clinical Commissioning Group (CCG) (previously known as Primary Care Trust/PCT) to ensure that they are aware of the guidance and are keeping to it. You may also find it helpful to use this letter if you live in Scotland, Wales or Northern Ireland. The letter can be downloaded here:

www.gov.uk/government/publications/importance-of-finger-prick-tests-in-managing-type-1-diabetes

In Northern Ireland, the Health and Social Care Board have released regional guidance on the self monitoring of blood glucose (SMBG) for people with Type 2 diabetes. The letter outlining this guidance, and the guidance itself can be downloaded from the HSC Board website here:

www.hscboard.hscni.net/medicinesmanagement/Prescribing%20Guidance/Self%20Monitoring%20of%20Blood%20Glucose/index.html#P-1_0

What can I do to challenge the restriction of my test strips?

In the first instance you should contact your GP and ask for clarification about why the decision to stop or reduce your test strips has been made. You will need to find out if this is a decision that your diabetes healthcare team has made based on your personal circumstances, or if it is because of a blanket restriction made by your healthcare provider that does not take into account your individual needs.

How can Medicines Use Reviews help?

If you have a long term condition such as diabetes you are entitled to a Medicines Use Review. This is a free NHS service offered by pharmacists in the UK to help you get the best out of your medicines. In this consultation you can highlight if you are experiencing a restriction of test strips, and the impact this is having on your diabetes care. The pharmacist will fill in a form called a Medicines Use Review action plan so that you have a record of what was discussed, and a copy will go to your GP. This report could indicate if you are experiencing difficulties in access to test strips and recommend an increase in amount prescribed.

For further information about Medicines Use Reviews visit www.rpharms.com/health-campaigns/medicines-use-review.asp.

What do I do if my GP and/or diabetes healthcare team has reviewed my need for test strips based on individual need?

Any decision made about your need for test strips should have been reached in partnership with you in a joint decision making process. If the decision to stop or restrict the number of test strips prescribed to you has been made by your GP or healthcare team without you, you will need to make a case for why you need to continue testing and the number of times you need to test. This should include details of how you use your test results and what actions you take based on them.

This issue can only be resolved through talking with your GP or healthcare team and may depend on the individual case you make for testing. If the decision is still to restore or restrict the number of test strips, it is important you meet with your GP or healthcare team to discuss the decision. Make sure you fully understand why this decision has been made. If your GP or healthcare team feels that your current home monitoring is not effective and you are not acting on the information appropriately, you can ask for further education to help enable you to manage your monitoring.

What do I do if my healthcare provider has set a restrictive policy?

If your GP or other healthcare professional is restricting the number of test strips prescribed because of a formal restrictive policy across your whole area, contact your healthcare provider requesting a copy of the policy, which may have been produced as guidance, and details of how and why this decision was made. Don't take for granted that your surgery manager or GP are following guidelines in the intended

way so ask your GP for their understanding of the guidelines and request to see any information they have on this subject. If you feel your surgery is being too rigid in their understanding of such guidance you can challenge it, put forward your interpretations and attempt to reach a mutual agreement.

How do I make my case for testing?

Several points are made below. You can choose those relevant to you based on the type of diabetes you have, the treatment(s) you use to manage your diabetes, and the particular problems you are experiencing in accessing test strips at the moment. Be sure to expand these points in full to stress the benefit that testing is giving you, and the impact any restriction is having. Contact the Diabetes UK Advocacy Service if you need help with this.

- Emphasise the action, or actions, you take after doing blood glucose tests and stress how using test strips is central to enhancing your self-management.
- Explain if you are at risk of hypos, ketoacidosis or hyperglycaemia.
- If you drive and your diabetes medication could cause you to experience hypoglycaemia.
- If you carbohydrate count.
- If you want to optimise glycaemic control prior to conception.
- If you are breast feeding.
- If you want to optimise glycaemic control during pregnancy.
- If you are very active and regularly take part in intensive physical activity such as running, swimming, or gardening.
- If you have a job that requires pro-active self-management, particularly to avoid hypoglycaemia
- If you live alone.
- If you are at an increased risk of falls
- Suspected or confirmed unawareness of hypoglycaemia.
- Look at the records of your HbA1c results over a period of time (eg the last four results). If your results were outside the target range of 48 mmol/l or below, say how you use your test strips to support your self-care to improve your control. If your HbA1c is within the target range you need to stress how you use your test results to achieve and maintain this. It is important that people with diabetes are taught how and when to use blood glucose tests and how to use the results as part of diabetes self-care. You can find information on blood glucose targets on our website at: **www.diabetes.org.uk/glucose-targets** or alternatively contact the Diabetes UK Careline **0845 120 2960**.
- The diabetes national service framework (NSF) published in 2001 focuses on making sure that people with diabetes are able to increase their personal control over day-to-day management of their diabetes. Home monitoring through blood and urine testing is an appropriate means of supporting self-management for some people. The national service frameworks are available online at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002951. These are on the archived Department of Health website, new service frameworks will be on the gov.uk website. NICE has now published a quality standard for diabetes (2011) which supports the existing NSF and provides an authoritative definition of good quality care (Diabetes in adults QS6). Available online at guidance.nice.org.uk/QS6
- NICE has produced guidance on self-monitoring for people with Type 2 diabetes which highlights the role of blood glucose monitoring as part of an integrated self-management package. This guidance, Type 2 Diabetes: the Management of Type 2 Diabetes (update), (reference number CG66) can be found online at www.nice.org.uk/CG66, and has been partially updated by Type 2 diabetes-newer agents (CG87), available at www.nice.org.uk/CG87.
- Diabetes UK produces a free leaflet called Diabetes Care and You that includes information about the need for self-monitoring and target ranges. This leaflet can be downloaded for free via our website www.diabetes.co.uk/onlineshop or ordered via our publication orderline **0800 585 088**.
- Include reference to the relevant Diabetes UK position statement on self-monitoring of blood glucose and the points made.

What can I do if I am unhappy with the response I receive?

If you are not satisfied with the response you receive you have the right to complain and have your complaint investigated. All NHS healthcare providers and service providers, eg GP, dentists, opticians and pharmacists must have a complaints procedure. They must publicise their procedure and give clear information about how to make a complaint. Ask a member of staff for details or look on the surgery, hospital or trust's website or contact the complaints department for a copy of the complaints procedure.

A complaint can be made verbally or in writing, including email. It is useful if your complaint is in writing. You should make it clear that you wish the complaint to be investigated under the NHS complaints procedure and include the following information:

- full details of the matter you are complaining about
- what you would like to see as a result of the complaint, eg an explanation or apology or change to the system.

You may want to enclose a copy of Diabetes UK's position statement 'Self monitoring of blood glucose levels' if appropriate with your letter. See page 7 for the position statement for Type 1 diabetes, or page 10 for the position statement for Type 2 diabetes. They can also be downloaded from the Diabetes UK website, or requested from the Diabetes UK Careline.

Keep copies of all letters sent and received and send photocopies, not originals, of any documents you are including. You should expect an acknowledgement letter in two to three working days. If your complaint is regarding primary care, eg your GP, you should receive a full response within 10 working days, and if it is regarding hospital/secondary care within 25 working days. If your complaint is going to take longer you should be kept informed.

You may also like to contact your MP to discuss the issue.

Who can help me complain?

In England

- The Patient Advice and Liaison Service (PALS). PALS offers confidential advice, support and information on health-related matters to patients, their families, and their carers. PALS staff are NHS employees, who can help with health-related questions and with resolving concerns or problems when using the NHS. This includes giving information about the NHS complaints procedure and how to get independent help if you want to make a complaint, including NHS Complaints Advocacy services. You can ask your GP surgery or hospital for details of your nearest PALS, or phone NHS Direct (or NHS 111 if it is available in your area).
- NHS Complaints Advocacy Services. The NHS Complaints Advocacy service is a confidential, free and independent service that can help you make a complaint about a National Health Service (NHS). NHS Complaints advocates can help you explore the options available to you at each stage of the complaints procedure, talk with you about what support you need to make your complaint, give you information about the different ways that you can raise your concerns and help you to think about what you would like to achieve from your complaint. If you choose to pursue your complaint yourself, they can provide you with a self help pack.

  NHS Complaints Advocacy services are commissioned by local authorities, and replace the former Independent Complaints Advocacy Service (ICAS) which helped people wishing to make a formal complaint about an NHS practitioner or service. For more information on the NHS Complaints Advocacy service in your area, you can visit the NHS Complaints Advocacy service website at nhscomplaintsadvocacy.org, or you can contact the service directly.

Please see 'Sources of Support and Information' at the end of this pack for more information on contacting the above services.

In Scotland

- The Patient Advice and Support Service (PASS). PASS is part of the Scottish Citizen's Advice Bureau (CAB) Service and provides free confidential information, advice and support to anyone who uses the NHS in Scotland. PASS can provide information on rights and can help people to make comments and complaints about the care provided by the NHS

in Scotland. (Please see 'Sources of Support and Information'at the end of this pack for more information on contacting PASS).

In Wales

- Community Health Councils (CHCs). CHCs are independent organisations which provide help and advice if you have problems with or complaints about NHS services. Each CHC has a complaints advocacy service to assist with individual complaints. (Please see 'Sources of Support and Information' at the end of this pack for more information on contacting your local CHC).

In Northern Ireland

- The Patient and Client Council. The Council provides free and confidential advice, information and help to make a complaint. (Please see 'Sources of Support and Information' at the end of this pack for more information on contacting the Patient and Client Council).

Citizen's Advice Bureau (CAB) throughout the UK can provide advice and information on making complaints, including how to find independent advocacy to help you put across your case, for example, if you are a mental health service user or have learning difficulties. (See "Sources of Support and Information" at the end of this pack for more information on contacting the CAB).

What is Diabetes UK doing about this issue?

- Diabetes UK has carried out extensive work to identify the source of, and then influence, the decision made to restrict the number of test strips people with diabetes are being prescribed. We have written to prescribing advisors of healthcare providers asking for a copy of any policies and reinforcing the position that access to strips with education should be on the basis of individual clinical need and informed choice. We have identified a number of areas with restrictive policies and have contacted them directly.
- We provide the secretariat for the All Party Parliamentary Group for diabetes (APPG). In Autumn 2012 we attended a meeting with the APPG to highlight that test strips are being restricted nationally, and the impact that this is having.
- We completed two surveys during 2013, one online and one through Careline to establish the extent and nature of restrictions on access to test strips, and the impact this is having on people with diabetes. The results will be published, and we will use the data to highlight this issue in media work throughout 2013.
- Further work is planned for 2013, including the publication of an extensive report. This will include data from our two surveys, and case studies from people who have experienced a restriction of test strips.
- We are working with 'Diabetes Voices' about this issue. This is one of our volunteer teams who help us make a difference by working alongside us to campaign and influence for change. You may want to raise your voice and make a difference to diabetes services and care. You can find further information about joining Diabetes Voices and sign up at www.diabetes.org.uk/diabetesvoices, or by phoning the Diabetes Voices team on 020 7424 1008.

DIABETES UK'S POSITION STATEMENT

Self-monitoring of blood glucose for people with Type 1 diabetes

Key points

- Self monitoring of blood glucose levels should be regarded as an integral part of treatment for everyone with Type 1 diabetes and access to blood glucose testing strips and meters should not be restricted.
- Self monitoring of blood glucose levels can improve glycaemic control in a person with Type 1 diabetes and reduce the incidence of the long term complications of diabetes.
- Use and frequency of testing, and target blood glucose level, should be agreed between the person with Type 1 diabetes and their diabetes healthcare team.
- Access to self monitoring test strips should be based on individual need in a joint decision making process between the person with diabetes and their clinician.
- Treatment regimen, lifestyle and individual needs will determine how frequently a person with Type 1 diabetes needs to test.

- Self-monitoring skills should be taught close to the time of diagnosis and initiation of insulin therapy. The education should enable self monitoring of blood glucose levels and the individual able to adjust treatment and activities appropriately. This will help to avoid hypoglycaemia, control hyperglycaemia and support optimal diabetes outcomes.
- Self monitoring should be performed using meters and strips that suit a person with Type 1 diabetes requirements, usually with low blood requirements, fast analysis times and integral memories.
- Structured assessment of self-monitoring skills, the quality and use made of the results obtained and the equipment used should be performed annually, or more frequently according to need, and reinforced where appropriate.

Introduction

Over the last two decades it has been firmly established that tight glycaemic control is associated with a significant reduction in serious long term diabetes related complications. In people with Type 1 diabetes a landmark study clearly showed that self monitoring of blood glucose, together with a range of interventions, improved long term glycaemic control[1]. It is widely recognised that SMBG is beneficial, when supported by education, for all people with Type 1 diabetes[2].

Self monitoring of blood glucose levels should be a core component of self management in people with Type 1 diabetes when used as part of an integrated package with ongoing education and assessment regarding the interpretation of results and use made of the results obtained. This position statement is guidance for adults with Type 1 diabetes. The figures suggested are guidance on the absolute minimum of test strips required and in many circumstances people with Type 1 diabetes will need to do more tests. The number of test strips prescribed should be decided by a joint decision between clinician and the person with diabetes. A decision on number of tests strips should always be made on a patient by patient basis.

Current situation

Research in 2005 found that 27 per cent of PCTs in England reported the existence of a policy restricting the provision of blood glucose test strips for people with diabetes[3]. Restriction mainly focused on people with Type 2 diabetes however Diabetes UK have collected further evidence showing that people with Type 1 diabetes are increasingly finding access to blood glucose test strips and their choice of meter is being restricted.

Recent personal correspondence with PCTs and local health boards has found access to blood glucose test strips for people with Type 1 diabetes is dependent on geographical variation and not always based on need or research evidence with the number of strips being prescribed on a monthly basis for a person with Type 1 diabetes varying considerably and often falling short of our previous recommendations[4].

It seems likely financial constraints are causing restrictions on the numbers of test strips being prescribed and lack of choice on meters. Although costs are of increasing importance within the current climate in the NHS, we are concerned that cost should not become the leading criteria on which prescribing decisions are made.

A systematic review showed SMBG to be associated with improvements in diabetes control but recommended further robust research may be beneficial in identifying the optimum frequency of SMBG in people with Type 1 diabetes[5].

A number of guidelines exist for the use of self monitoring of blood glucose levels for people with Type 1 diabetes[2, 5, 6, 7] including our own care recommendations[4]. In the absence of further evidence following the publication of our own consensus guidance we still broadly support these recommendations with some revisions.

Healthcare professionals are encouraged to work in partnership with people with diabetes to discuss and agree together frequency of testing according to individual needs and circumstances.

- The frequency of testing should be agreed between the person with diabetes and their health care team.
- As a general rule, the more intensive therapy the more blood glucose tests may be needed, but

this should be agreed between the person with diabetes and their diabetes team.

- Those injecting one or two times per day should be educated to undertake SMBG at least two times a day, varying the time between fasting, pre meal and post meal, to identify trends. This is the absolute minimum and more testing may be required.
- Those who alter insulin doses at mealtimes should be encouraged to monitor at least four times daily. This is the absolute minimum and more testing may be required.
- More frequent self monitoring during illness is recommended and testing should be done at least four times a day and appropriate action taken. This is the absolute minimum and more testing may be required.
- It is recommended that people using insulin pump therapy should monitor their blood glucose levels at least 4–6 times daily. This is the absolute minimum and more testing may be required.
- More frequent monitoring will be required during establishment of pump therapy.
- More frequent self monitoring during illness with appropriate action taken is recommended for those on pump therapy.
- During pregnancy NICE recommend to test fasting blood glucose levels and blood glucose levels one hour after every meal and before going to bed[8]. To enable insulin adjustment pre meal testing is necessary so at least seven tests per day are needed. Extra testing is likely to be needed with the increased incidence of hypos caused by striving to achieve tighter diabetes control.
- In addition to these recommendations someone driving will need to carry out more testing to meet DVLA guidance. Since 2011 the DVLA requires drivers with a Group 1 licence (cars, motorcycles) on insulin test their blood glucose levels before driving and at no longer than 2 hourly intervals during a long period of driving. Group 2 (lorries/ passenger carrying vehicles) drivers with insulin treated diabetes must monitor blood glucose at least twice daily and at no longer than 2 hourly intervals during a long period of driving using glucose meter with a memory function[9].

Circumstances when more frequent testing will also be required include:

- People who carbohydrate count.
- Suspected or confirmed unawareness of hypoglycaemia.
- Regular and/or severe hypoglycaemia.
- Intensifying or changing treatment regimes to improve glycaemic control.
- Unplanned activity.
- Regular and/or intensive physical activity such as running, swimming, scuba diving or gardening.
- Optimising glycaemic control prior to conception.
- Breast feeding.
- Shift work/ jobs that require proactive self-management, particularly to avoid hypoglycaemia.
- People living alone.
- People who may be at increased risk of falls.

Diabetes UK calls to action

- Decisions about blood glucose monitoring should be made on a case-by-case basis and in consultation between the person with Type 1 diabetes and not by blanket removal of strips from prescriptions or local restrictive policies.
- Appropriate self monitoring and education should be provided showing people how to interpret results to adapt diet, lifestyle and medication to achieve optimal outcome.
- Self monitoring of blood glucose levels should be part of an integrated package of care as defined by national guidelines.
- Further high quality research is needed looking at the benefits of self monitoring and optimal frequency in people with Type 1 diabetes.
- A choice of blood glucose meters should be available that is suitable for individual need in relation to user acceptability and ease of use.

Conclusion

People with Type 1 diabetes should not be subjected to a restriction on blood glucose testing strips and choice of meter. Decisions should be made on the basis of need, in discussion with the person with Type 1 diabetes and jointly agreed with the person with diabetes and their healthcare team.

References

(1) Diabetes Control and Complications Trial Research Group: The effect of intensive treatment of diabetes on the development and progression of long term complications in insulin dependent diabetes.N Eng J med. 1993:329:977-986

(2) NICE. Type 1 diabetes: diagnosis and management of Type 1 diabetes in adults. Clinical guideline 15.

(3) Your Local Care. Diabetes Services in England. Research by Diabetes UK and Dr Foster. 2005

(4) Self monitoring of blood glucose. Diabetes UK care recommendation. January 2009

(5) Optimal therapy report. Systematic review of use of Blood Glucose Test Strips for the Management of Diabetes Mellitus. Canadian Agency for Drugs and Technologies in health.Vol 3 ,issue 2.2009

(6) American Diabetes Association: standards of medical care in diabetes (position statement). Diabetes Care.2012; vol 35 Supplement 1 S11-S63

(7) SIGN 116.Management of diabetes. A national clinical guideline. March 2010

(8) Diabetes in pregnancy. Management of diabetes and its complications from pre-conception to the post natal period.

(9) At a glance guide to the current Medical Standards of Fitness to Drive DVLA.2012 (including information for drivers booklet).

Position Statement reviewed August 2012.

Due for review August 2014.

DIABETES UK POSITION STATEMENT

Self monitoring of blood glucose (SMBG) for adults with Type 2 diabetes

Key points

- Self monitoring of blood glucose levels in people with Type 2 diabetes on insulin should be regarded as an integral part of treatment and should not be restricted.
- Self monitoring of blood glucose levels should be available to people receiving sulphonylurea and prandial glucose regulators because of the risk of hypoglycaemia in these groups.
- Blanket policies should be removed with access to self monitoring for people not in the above treatment groups based on an individual assessment whereby all options are explored in a joint decision making process between the person with diabetes and their clinician to ensure resources are adequately used.
- Where a decision has been made that SMBG is appropriate, use and frequency of testing and target blood glucose, should be agreed between the person with diabetes and their healthcare team.
- If SMBG is appropriate self monitoring should be performed using a meter that suits a person with Type 2 diabetes requirements.
- Arbitrary withdrawal of SMBG in those who do not take insulin but clearly benefit from doing so should not occur.
- SMBG should be integrated with a care package, accompanied by education and should enable the individual to interpret results and adjust treatment accordingly or inform their healthcare team.
- People carrying out testing should be able to discuss with their healthcare team their reasons for testing and frequency, how they are interpreting and acting on the results.
- Structured assessment of self-monitoring skills, the quality and use made of the results obtained should be performed annually, or more frequently according to need, and reinforced where appropriate.
- Commissioners of services should re examine their policies in place re provision of meter choice, testing strips and education supporting clinicians to carry out individual assessment thereby ensuring effective use of finite resources.

- The Department of Health, the pharmaceutical industry and commissioners of services should together review the cost of testing strips and together negotiate a reduction in cost to the NHS.

Introduction

Over the last two decades it has been firmly established that tight glycaemic control is associated with a significant reduction in serious long term diabetes related complications. Self-monitoring of blood glucose is an effective tool in the self-management of glucose levels in people with Type 1 diabetes and people with Type 2 diabetes using insulin therapy. It helps people with diabetes using insulin achieve tight glycaemic control and to identify low blood glucose levels before the development of severe hypoglycaemia.

The exact role of SMBG for people with Type 2 diabetes who are not on insulin is less clear and has been widely debated. Critics say that there is no cost effective benefit, that the overall effect of self monitoring is small up to six months after initiation, and subsides after 12 months, as highlighted in a recent systematic review[1].Supporters (including people with Type 2 diabetes) say that there are significant quality of life and patient satisfaction benefits which empowers people to self-manage their diabetes and these outcome measures were not measured in most of the studies evaluated[1].

Ultimately, the lack of clinical evidence does not mean there is no evidence but that it has not been possible to gather and interpret it. Therefore this paper explores the issues of importance concerning access to and appropriate use of SMBG by those who live with Type 2 diabetes and how this can best be tackled in relation to the increasing costs associated with diabetes in the UK.

Current situation

The prevalence of Type 2 diabetes is rising in the UK dramatically and since 1996 the number of people diagnosed with the condition has increased from 1.4 to 3 million[2].The spend on blood glucose testing strips in England in primary care in 2010 was approximately £150 million. This compares to approximately £300 million on insulins and £250 million on antidiabetic drugs[3].

The number of blood glucose testing items prescribed increased by 6 per cent over the period 2005/6 to 2010/11[3] though it must be remembered the number of people diagnosed with diabetes also increased during this period.

The volume and cost of prescriptions for blood glucose monitoring is rising steadily. The current spend on blood glucose testing items per person on the diabetes QoF register is £60.88[4] and spend per person on the diabetes Quality and Outcomes Framework register in England is £588.90[4].However, it is important to note this includes both people with Type 1 and Type 2 diabetes as there are no separate figures available.

Usage rates of blood-glucose testing strips vary widely across England. The patterns of this variation do not correlate with the national distribution in the incidence of Type 2 diabetes.

Meters are relatively cheap (approximately fifteen pounds upwards if bought over the counter) but most manufacturers provide them free of charge through the NHS for distribution to patients via health care professionals[5]. The main cost is therefore the test strips, at approximately fifteen pounds for a pack of 50 (NHS 2012 price) or £20–25 if bought over the counter (2013 price).

In 2006 the cost of blood glucose testing strips was reduced by 12 per cent from the beginning of October 2006, after agreement between the Department of Health and the manufacturers[6].

A systematic review of the evidence was commissioned by the National Institute for Health Research Health Technology Assessment programme[5]. Their findings informed the work of the NHS Diabetes Working Group, of which Diabetes UK were stakeholders, examining the role of SMBG in people with Type 2 diabetes[7].They found:

- SMBG could motivate and improve diabetes self-management in some people by informing them in real time of the impact of any lifestyle changes and helping them self manage their diabetes by following a healthy lifestyle. This is a benefit experienced by people with Type 2 diabetes in the workshop we ran in November 2012.

- SMBG can provide reassurance, empower them to take control over their healthcare and understand the relationship between how they are feeling and their blood glucose readings.
- In people with Type 2 diabetes managed by oral medication or through lifestyle changes, when used as part of a structured education plan, notable reductions in HbA1c were observed.
- At a recent meeting with our Council of People with Diabetes several people with Type 2 diabetes reported that they found SMBG beneficial in improving diabetes control, motivating and helping them adhere to a healthy diet and lifestyle.

Conversely the systematic review found that SMBG was not beneficial[7]:

- In some individuals SMBG caused deterioration in psychosocial outcomes including anxiety and depression though it has been acknowledged this could be because the person with diabetes was not given the education to interpret the data and therefore be burdened by the information as opposed to being empowered by it.
- There was a lack of interest in the results from health care professionals though this may be because of a mismatch in expectations, with the professionals expecting patients to use SMBG to self manage and patients expecting the health care professional to use the result to adjust treatment. Failure to act on the results was common though this may be linked to a lack of education in how to interpret the blood glucose results and what to do with the information. It is worth noting that unless offered education by healthcare professionals, individuals who purchase a blood glucose meter from pharmacists or stores will have received no training on how to use it as part of their diabetes self management. The meter pack only contains basic instructions with no guidance on how to integrate the information into an individual's care plan.
- Though the systematic review revealed there was a small reduction of HbA1c, this was not thought to be clinically significant though. However, there is a lack of agreement amongst healthcare professionals what represents a clinically significant change in HbA1c.

As previously highlighted, a more recent systematic review has supported these findings in people whose Type 2 diabetes is not treated by insulin[1].

NICE clinical guidelines CG87[8] recommends SMBG is appropriate for some people with Type 2 diabetes and should be available to:

- those on either insulin treatment or on oral glucose-lowering medications to provide information on hypoglycaemia (again noting this guidance is not relevant to metformin as it does not cause hypoglycaemia if used in isolation).
- assess changes in glucose control resulting from medications and lifestyle changes.
- Monitor changes during intercurrent illness.
- Ensure safety during activities, including driving.

NICE guidance also states if self monitoring is appropriate, but blood glucose monitoring is unacceptable to the individual, there should be a discussion about the use of urine glucose monitoring.

NICE guidance concerning SMBG in pregnancy recommends increased frequency of glucose monitoring to achieve optimal blood glucose control to reduce the risk of miscarriage in the first trimester and congenital malformations[9].

Furthermore the DVLA requires some treatment groups to carry out testing for safety reasons[10]:

- Group 1 (cars, motorcycles) and Group 2 (lorries/ passenger carrying vehicles) licence holders on insulin are required to carry out appropriate blood glucose monitoring at least twice daily and two hourly during a long period of driving using a meter with memory function.
- Group 1 holders managed by tablets which carry a risk of causing hypoglycaemia (this includes sulphonylureas and prandial glucose regulators) – the DVLA stipulates that it may be appropriate to monitor blood glucose regularly and at times relevant to driving to enable the detection of hypoglycaemia.
- The DVLA stipulates that Group 2 drivers managed by oral medication which carries a risk of hypoglycaemia must regularly monitor blood glucose daily and at times relevant to driving.

Research in 2005 found that 27 per cent of PCTs in England reported the existence of a policy restricting the provision of blood glucose test strips for people with diabetes[11]. Restriction was mainly focused on people with Type 2 diabetes[11].At a workshop at our 2009 Annual Professional Conference, patients and industry representatives reported that GPs were rationing test strips for individuals with diabetes.

There is a call from some quarters that the NHS could save resources by simply refusing to reimburse the cost of meters and strips for those on oral agents[7].

Some people with Type 2 diabetes need to test and are clearly benefitting from self monitoring, but we are increasingly aware that a blanket ban is being applied to them and they are experiencing a restriction on blood glucose testing strips and their choice of meters irrespective of how they treat their diabetes. Preliminary results from two surveys we have started this year support this statement[12, 13].

Recent correspondence with several Primary Care Trusts (now Clinical Commissioning Groups), NHS Boards and local health boards has revealed policies in place where only a very small range of meters is available on prescription and there is a restriction on test strips for certain treatment categories.

Access to testing strips is dependent on geographical variation and there appears to be little standardisation of usage within Primary Care Trusts[11].It seems likely financial restraints are causing restrictions on the number of test strips being prescribed and lack of choice on meters. Although costs are of increasing importance within the current climate in the NHS, we are concerned that costs should not be the leading criteria on which prescribing decisions are made. However we acknowledge indiscriminate prescribing cannot continue.

Diabetes UK calls to action or recommendations

Diabetes UK

- Collate and publish the results of the 3 month audit (January–March 2013) carried out by our Careline team and Advocacy manager assessing the extent of restriction of tests strips for adults with Type 2 diabetes and any resulting impact.
- Collate and publish the results of our online survey commenced February 2013.
- With facilitation by our 'Involvement and Improvement team' involve the members of one of our voluntary teams 'Diabetes voices', to work alongside us to challenge and influence individual prescribing decisions and local protocols where appropriate.
- To develop an online decision resource and education material to help inform people with Type 2 diabetes about how to use SMBG effectively.

Healthcare professionals

- Healthcare professionals should work in a supportive care planning partnership together with the person with diabetes, to assess whether self monitoring of blood glucose levels is appropriate. This involves carrying out an individual assessment, discussing options and making an agreed/joint decision based on individual needs and circumstances to ensure resources are adequately used.
- Healthcare professionals should encourage those who treat their diabetes with insulin or medication that can cause hypoglycaemia to continue to monitor for safety reasons.
- Similarly healthcare professionals should encourage people with non-insulin treated diabetes who are motivated by SMBG and who use the information to maximise the effect of lifestyle and medication in self management to continue to monitor.
- The consultation should address use and frequency of testing, and target blood glucose level and be agreed between the person with Type 2 diabetes and their health care professional team.
- SMBG should be integrated within a care package, accompanied by education which includes self monitoring of blood glucose levels that enables the individual to interpret results and use the data to reinforce lifestyle change, adjust treatment and activities or inform their healthcare professional. The person's treatment regimen, lifestyle and individual needs should be taken into account to determine, if blood glucose testing is appropriate, and how frequently the person with diabetes needs to test. Education should

not only cover how to adjust treatment, but also 'motivational knowledge' that shows why good control is so important.

- Health care professionals should be trained in the use of SMBG to support individual's changes in lifestyle and self adjustment of medications where appropriate and to stop monitoring in those who don't find it of any benefit.
- Health care professionals may wish to reflect on their practise concerning SMBG. This could include whether they provide education concerning SMBG, carry out appropriate and timely reviews of people who SMBG and whether they look and act on people's results. Structured assessment of self-monitoring of skills, the quality and use made of the results obtained and the equipment used should be performed annually, or more frequently according to need, and reinforced where appropriate.
- At a time of financial pressures within the NHS, health care professionals have a responsibility to ensure resources are used wisely. Healthcare professionals should undertake regular reviews to identify and support those who find SMBG useful while identifying those who gain no benefit in testing. It has been questioned[8], and also raised in the focus work we have carried out with the Council of People with Diabetes, whether SMBG needs to be performed indefinitely. Testing for a defined period only may be an appropriate way of informing people with diabetes about the effect of treatment and management on their blood glucose levels and an assessment of whether it is of benefit or causing harm. Care must be taken about how this is managed so as not to raise expectations and then withdraw equipment inappropriately.
- Healthcare professionals should not carry out arbitrary withdrawal of SMBG in those individuals who do not take insulin but clearly benefit from measuring their glucose.
- The system of selling SMBG meters by pharmacists should be reviewed to avoid people with Type 2 diabetes buying meters inappropriately and to ensure effective education is provided as part of a structured programme of care.
- For those people not benefitting from SMBG, or who do not wish to continue, consideration should be given to having their HbA1c monitored more than once a year. All people with diabetes should have their HbA1c measured annually as a minimum. The frequency should be determined on a case by case basis.
- To support those who are not finding SMBG useful and to help to ensure they are not made to feel guilty about not testing their blood glucose levels.

Adults with Type 2 diabetes

- People with diabetes also have a responsibility to ensure resources are used wisely and may wish to reflect on their own behaviour concerning SMBG. Questions they may wish to consider include what will they do with the results, what are their goals for SMBG, what difference will doing this test make and is testing appropriate ie the right number of times or at the right times?
- To acknowledge if SMBG is negatively impacting on their life and address with their healthcare professional any issues they are facing before requesting another repeat prescription. This will enable a decision to be made as to whether it is appropriate to continue with SMBG or to stop. However before a decision is reached to stop, it is important to establish that the person with diabetes has been given adequate education around SMBG to effectively self manage their diabetes.

Those who commission healthcare services

- Commissioners to examine their approach in the availability of blood glucose testing equipment (meters and strips) to increase value but ensure that people with Type 2 diabetes can choose an appropriate meter for their own needs.
- Blanket policies restricting the number of test strips or meter choices should be removed and focus placed on supporting clinicians on how to approach individual assessment and review to reduce waste and meet individual needs.
- Greater provision of education which includes self monitoring of blood glucose levels to be available for people with diabetes so they can use the equipment effectively.
- The Department of Health and commissioners of health services should investigate opportunities to negotiate further with all manufacturers a

reduction in the cost of blood glucose testing strips to the NHS through NHS procurement at a national level to reduce costs to the NHS and increase effectiveness.

Pharmaceutical industry

- To review the cost of blood glucose testing strips and consider a reduction in cost to the NHS.
- To critically appraise the educational literature accompanying meters and if appropriate work with Diabetes UK in the development of new resources.

Conclusion

A decision as to whether self monitoring of blood glucose monitoring is appropriate for adults with Type 2 diabetes should be based on an individual assessment, rather than blanket policies. The decision to use SMBG is based on an informed discussion between the person with diabetes and their healthcare professional where the risks, benefits and options for SMBG are explored fully. This process provides an opportunity to review use and reduce waste on a case by case basis.

Further information

Driving and diabetes position statement. Diabetes UK. 2012.

www.diabetes.org.uk/About_us/Our_Views/Position_statements/Driving-and-diabetes/

References

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(5) Self-monitoring of blood glucose in Type 2 diabetes: systematic review. C clar et al. Health Technology Assessment 2010; Vol.14:No.12.

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(9) NICE. CG63.Diabetes in pregnancy. Management of diabetes and its complications from pre-conception to the post natal period. 2008.

(10) At a glance guide to the current Medical Standards of Fitness to Drive.DVLA.2012 (including information for drivers booklet).

(11) Your Local Care. Diabetes Services in England. Research by Diabetes UK and Dr Foster 2005

(12) Careline survey,2013

(13) Online survey, 2013

Position statement reviewed April 2013.

Due for review April 2015.

Some useful sources of support and information

National Institute for Health and Clinical Excellence (NICE)

The Guidelines for Type 2 diabetes 2008 are available at: www.nice.org.uk/CG66, partially updated by Type 2 diabetes – newer agents www.nice.org.uk/CG87.

Diabetes UK Advocacy Service

The Advocacy Service provides advocacy for people with diabetes to help them express their views and wishes and access information and services.

Web www.diabetes.org.uk/How_we_help/Advocacy
Email advocacy@diabetes.org.uk
Telephone 020 7424 1840

Diabetes UK Careline

The Careline provides support and information to people with diabetes as well as friends, family and carers. Careline@diabetes.org.uk or call **0845 120 2960** (please check the costs of calls to 0845 numbers with your phone provider). Or call **020 7424 1000** and ask to be transferred to Careline.

Patient Advice and Liaison Service (PALS) (England only)

The Patient Advice and Liaison Service help resolve concerns or problems when you are using the NHS in England. They provide information about the NHS complaints procedure and how to get independent help if you decide you want to make a complaint. More information on PALS can be found on the NHS choices website at **www.nhs.uk/chq/Pages/1082.aspx**

You can ask your GP surgery or hospital for details of your nearest PALS, or you can phone NHS Direct on **0845 4647** (or NHS 111 if available in your area).

NHS Complaints Advocacy Service (England only)

The NHS Complaints Advocacy Service is a free and independent service that can help you make a complaint about an NHS service. Their website has information on how to make a complaint and the support they can provide. They also have a self help pack which you can request or download.

If you would like an advocate to work with you, you can contact the service by e-mail or by calling their helpline. Alternatively you can use the website to search for your nearest NHS Complaints Advocacy Office, and contact them directly.

Web nhscomplaintsadvocacy.org
Email nhscomplaints@voiceability.org
Telephone 0300 330 5454 (helpline)
Textphone 0786 002 2939

Patient Advice and Support Service (PASS) (Scotland only)

The Patient Advice and Support Service can be accessed through any Scottish Citizens Advice Bureau. PASS can explain the NHS complaint procedure and provide information and advice and practical support to help you make a complaint.

Web www.cas.org.uk

Citizens Advice Bureau (CAB)

In Scotland the Citizens Advice Bureau is tasked with providing help for people making complaints about healthcare. In other parts of the UK the CAB may be able to help with this as part of its general advice service. The CAB offers free, confidential, impartial and independent advice. Advisers can help fill out forms, write letters and negotiate with third parties. Advice is available face-to-face and by telephone and some also provide email advice. The number of your local CAB will be in the phone book or you can also find your local CAB on their website.

Web www.citizensadvice.org.uk
www.adviceguide.org.uk to find online help from citizens advice
Telephone 020 7833 2181 to find your local CAB office

Community Health Council (CHC) Wales

The Community Health Council can give free impartial advice and help with making a complaint about healthcare in Wales.

Web www.patienthelp.wales.nhs.uk
Email enquiries@waleschc.org.uk
Telephone 0845 644 7814/02920 235 558
Address Board of Community Health Councils in Wales, 2nd Floor, 33–35 Cathedral Road Cardiff, CF11 9HB

Patient and Client Council (PCC) (Northern Ireland only)

The Patient and Client Council provide free impartial advice and help to people making a complaint about healthcare in Northern Ireland.

Web www.patientclientcouncil.hscni.net
Email using online contact form or info.pcc@hscni.net
Telephone 0800 917 0222

Parliamentary and Health Service Ombudsman (PHSO) (England Only)

The Ombudsman investigates complaints about the National Health Service (NHS) in England. The Health Service Ombudsman covers NHS hospitals, trusts and health authorities, GPs, dentists, opticians, pharmacists and other providers (including private health care) where the service is paid for by the NHS.

Web www.ombudsman.org.uk
Email phso.enquiries@ombudsman.org.uk
Telephone 0345 015 4033 (Complaints helpline)
Address The Parliamentary and Health Service Ombudsman, Millbank Tower, Millbank London SW1P 4QP

Scottish Public Services Ombudsman (SPSO)

The Ombudsman is the final stage for complaints about organisations providing public services in Scotland.

Web www.spso.org.uk
Telephone 0800 377 7330 (advice line)
Address SPSO, Freepost EH641, Edinburgh EH3 0BR

Public Service Ombudsman for Wales

The Ombudsman looks into complaints about public service providers in Wales including the NHS.

Web www.ombudsman-wales.org.uk
Telephone 0845 601 0987 (complaints advice)
Address Public Services Ombudsman for Wales, 1 Old Field Road, Pencoed, Bridgend, CF35 5LJ

Northern Ireland Ombudsman

The Ombudsman considers complaints against the NHS in Northern Ireland.
Web www.ni-ombudsman.org.uk
Telephone 02890 233821 or 0800 34 34 24 (freephone)
Address The Ombudsman, Freepost BEL 1478 Belfast, BT1 6BR

Patients Association

The Patients Association provides independent information and advice on a range of healthcare issues. They campaign on behalf of patients and are interested to hear about any aspect of the patient experience.

Web www.patients-association.org.uk
Email helpline@patients-association.com
Telephone 0845 608 4455
Address The Patients Association, PO Box 935 Harrow, Middlesex, HA1 3YJ

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0800 585 088 or visit **www.diabetes.org.uk/Shop**

Diabetes UK website: www.diabetes.org.uk

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This information should not be considered a complete guide to the law, which also changes from time to time. Legal advice should always be taken if in doubt. Diabetes UK is unable to give legal advice.

DIABETES UK
CARE. CONNECT. CAMPAIGN.

About Diabetes UK

Diabetes UK is the charity for people with diabetes, their family, friends and carers.
Our mission is to improve the lives of people with the condition and work towards a future without diabetes.

Diabetes UK is one of the largest patient organisations in Europe. We stand up for the interests of people with diabetes by campaigning for better standards of care. We are the largest funder in the UK of research into better treatments for diabetes and the search for a cure.

We provide support and information to help people manage their diabetes.

Useful contacts

Diabetes UK Careline: 0845 120 2960*, Monday–Friday, 9am–5pm

Diabetes UK's website: **www.diabetes.org.uk**
*Depending on your phone package, calls to 0845 numbers may be free. Please check with your phone provider for further details of costs to 0845 numbers. Alternatively, call **020 7424 1000** and ask Reception to transfer your call to the Careline.)

We welcome any feedback you may have on this or any of our information.

Please email **infofeedback@diabetes.org.uk**

Advocacy pack feedback form

Could you please take the time to fill out this evaluation form and return it to **Diabetes UK, Freepost LON 12857**. Your answers will help us to find out how useful the Advocacy Packs are and how we can improve them.

1 How did you use this pack?

Personally, to help yourself ☐ Professionally, to help a client ☐ General information ☐

2. How useful did you find this pack?

Very good ☐ Good ☐ OK ☐ Poor ☐ Very Poor ☐

3. What did you find most/least useful in the pack?

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4. Did the pack answer your questions? Yes ☐ No ☐ Partially ☐

Can you give details? ……

……

5. What changes would you make to the pack?

……

……

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6. How did you hear about the pack?

Friend/relative ☐ Healthcare professional ☐ Diabetes UK Careline ☐ Website ☐

Balance magazine ☐ Other ☐ Please specify: ……

7. What other subjects would you like an advocacy pack on?

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