

BETTER DIABETES CARE

A CONSULTATION DOCUMENT

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FOREWORD



The Scottish Diabetes Framework of 2002 and the Action Plan of 2006 were ambitious programmes designed to bring about real benefits for people in Scotland living with diabetes. Diabetes care in Scotland has undoubtedly improved significantly as a result, but there are still significant challenges.

The need to address those challenges is intensified by the rate at which the number of people living with diabetes is increasing.

Diabetes services, which are already working harder than ever, will need to continue to innovate and evolve in order to deliver care that is not only as efficient as possible but which is also fully responsive to the wishes of people with diabetes. To achieve this, we will need to take advantage of developments in research and in technology such as telehealthcare, while helping to strengthen the capacity of people with diabetes to influence services through their participation in the diabetes Managed Clinical Networks.

We want our revised Action Plan to link with and strengthen the health improvement work already under way to address the relevant risk factors, such as obesity, diet and physical activity, as well as the unacceptable health inequalities associated with diabetes. It must also consider specific issues of importance to people with diabetes such as structured education needs, the availability of insulin pump therapy and access to psychological care. The consultation is also an opportunity to consider what more we can do to recognise self management as a vital component of diabetes care.

I would like to thank Diabetes UK Scotland for its help in producing this consultation document. Its involvement during the consultation process will be crucial in helping us obtain a valuable insight into the needs and wishes of people with diabetes that will inform the core of our Diabetes Action Plan for the next 3 years.

I hope that you will take this opportunity to engage with our consultation and provide us with your ideas, views and aspirations for future diabetes care. The Scottish Government wants to continue the ambitious approach of previous work through the revised Action Plan which we intend to publish this November as our contribution to the 20th anniversary of the St Vincent declaration on diabetes care and research.

A handwritten signature in black ink that reads "Shona Robison". The signature is written in a cursive style.

Shona Robison
Minister for Public Health and Sport

1. INTRODUCTION

Diabetes

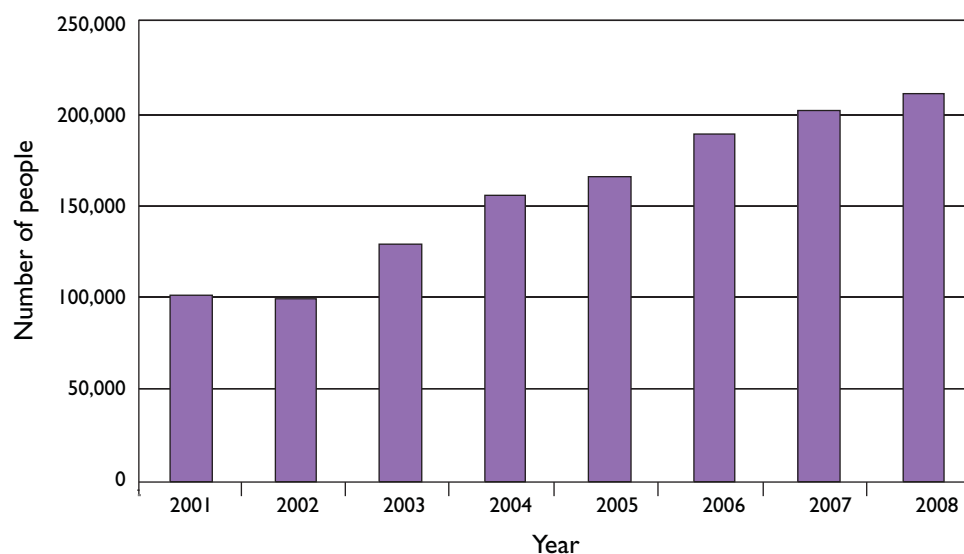
1.1. Diabetes Mellitus, recognised by an abnormally high blood glucose level, is the most common disorder of metabolism. Over 219,000 people, or one in twenty five of the Scottish population, have been diagnosed with the condition, and an estimated 90,000 remain undiagnosed.

1.2. There are two main types of diabetes; Type 1 and Type 2. About 13% of people with diabetes, or over 27,000 people in Scotland, have Type 1 diabetes. This develops when there is a severe lack of insulin in the body because most or all of the cells in the pancreas that produce it have been destroyed. Type 1 diabetes is one of the commonest long term conditions affecting children and adolescents in Scotland, which has one of the highest prevalence rates of Type 1 diabetes in Europe.

1.3. Type 2 diabetes develops when the body can still produce some insulin, although not enough for its needs, or when the insulin that the body produces does not work properly. Type 2 usually occurs in people over the age of 40 and its rise in prevalence is closely linked to rising obesity levels, the ageing population and reduced activity levels.

1.4. Over the past three years, Scotland has seen a steady increase in the incidence of diabetes (Fig 1). Although much of this rise can be attributed to better monitoring and data collection, it still represents a serious concern. This undesirable trend reflects what is happening in the rest of the UK and in other parts of the world. The number of people with Type 2 diabetes in Scotland is currently increasing at a rate of 4.9% per year.

Figure 1: Scottish Diabetes Survey 2008 – Number of people with diabetes 2001-2008



1.5. Diabetes has been recognised for some time as a classic example of a long term condition, both in terms of the growing number of people with Type 2 diabetes and in terms of the serious health complications it can cause. Maintaining and improving diabetes services against a backdrop of increased incidence and prevalence, with the consequent pressure on these services, is a challenging proposition.

1.6. Some Type 2 diabetes can be prevented, or its onset delayed. However, diabetes care accounts for some 10% of all NHS expenditure. Prevention of Type 2 diabetes, and the avoidance of the resulting complications would not only be extremely cost-effective, but even more importantly, would contribute greatly to people's quality of life. These facts provide the rationale for the 3-year Action Plan published in 2006 and continue to form the basis of this next phase.

1.7. This consultation process offers an opportunity to reassess the 2006 Action Plan's aims in the context of progress to date and future challenges.

1.8. *Better Diabetes Care* will build on the experience of implementing past strategies, by seeking views from those with a personal and a professional interest in diabetes on those areas of diabetes care where further work is needed, and on the priorities for the next phase of work, from 2009 to 2012.

2. PROGRESS IN SCOTLAND

Implementing the Action Plan

2.1. The *Diabetes Action Plan*, published in June 2006, set out an ambitious agenda for the period up to 2009. Its priorities were developed in response to the progress made on implementation of the Scottish Diabetes Framework (2002). (See Appendix I).

2.2. The Scottish Government's action plan, *Better Health, Better Care*, set out its approach to helping people to sustain and improve their health, especially in disadvantaged communities, through better, local and faster access to health care. The Diabetes Action Plan is being revised to align it with the mutual NHS described in *Better Health, Better Care*, where people are regarded as leading partners in their own care.

2.3. The Scottish Diabetes Group (SDG), chaired by Dr Donald Pearson, the Scottish Government's Lead Clinician for Diabetes, was established to oversee diabetes care across Scotland. It has representation from people with diabetes, voluntary sector organisations, researchers, a broad range of health care professionals and suppliers, and those involved in planning health care services at local, regional and national level. The diabetes Managed Clinical Networks in each NHS Board provide the SDG with regular reports on progress against each of the actions in the 2006 Plan.










2.4. The SDG is supported in the implementation of the Diabetes Action Plan by a number of subgroups:

- Diabetes Care Focus Group
- Ethnic Minorities
- Foot Care
- Psychology
- Type I Diabetes
- SCI-DC
- Education
- Retinopathy Screening

2.5. The SDG also works closely with a number of partners and stakeholders from all parts of the diabetes community on delivering the diabetes Action Plan. These include: Diabetes UK Scotland, the diabetes Managed Clinical Network in each NHS Board, the Scottish Study Group for the Care of Diabetes in the Young, the Scottish Public Health Network, the Scottish Diabetes Research Network, the Scottish Diabetes Education Network, Juvenile Diabetes Research Foundation, National Services Division, Diabnet and the Scottish Diabetes Industry Alliance.

2.6. The 2006 Action Plan set out nine aims to be addressed by 2009. This was described in the Action Plan as *9 by 9*. Regular reports from the diabetes MCNs have allowed an assessment of progress on the *9 by 9*. A detailed summary of progress can be found in Appendix II. An illustration of progress can be found in Table I below:

Table I.

<p>1. Improve the quality of care and outcomes for all people with diabetes and reduce inequalities.</p> 	<p>2. Ensure that all people with diabetes have access to effective retinopathy screening.</p> 	<p>3. Enhance patient self-care and self-management by ensuring that all people with diabetes in Scotland have access to appropriate information and education.</p> 
<p>4. Strengthen and develop diabetes Managed Clinical Networks in order to improve the effectiveness and efficiency of services for people with diabetes.</p> 	<p>5. Improvement in the quality of patient data in order to improve clinical management and service planning.</p> 	<p>6. Develop and support staff to enhance their knowledge and skills in caring for people with diabetes.</p> 
<p>7. Increase diabetes research in Scotland.</p> 	<p>8. Support initiatives to promote healthier lifestyles for people with diabetes and for the population as a whole.</p> 	<p>9. Improve the communication and dissemination of information about diabetes in Scotland.</p> 

2.7. Improved NHS performance

2.7.1. In March 2008, NHS Quality Improvement Scotland (NHS QIS) and Diabetes UK Scotland produced a report on performance in 2007 against the NHS QIS diabetes standards published in 2002. They found significant changes and improvements since the first review against standards in 2004, and they also found that patients were increasingly involved in planning and developing these services.

2.7.2. Key findings from the report were:

- There is good evidence that NHS Boards continue to provide a very high standard of clinical care;
- Scottish Care Information – Diabetes Collaboration (SCI-DC) had been rolled out across Scotland but further work was required to ensure the transfer of information from SCI-DC to GP practices. They also found a lack of data interfaces that would allow one data entry to populate both primary and secondary care systems; and
- Generally education is provided at the time of diagnosis and on an ongoing basis. However the information is provided in a variety of settings and patients have reported that this information is not always consistent.

2.7.3. Most NHS Boards now meet all the clinical management standards. This has been supported through the introduction of the Quality and Outcomes Framework (QOF) in the General Medical Services contract, particularly in supporting the routine collection of data.

2.7.4. NHS QIS identified particular concerns with:

- Lack of psychological support;
- Foot care; and
- Access to dietetics advice.

2.7.5. A summary of findings from Diabetes UK Scotland patient focus groups was also included in the NHS QIS report. Key issues highlighted in the focus groups were: lack of access to support for self-management; provision of information; lack of provision of psychological and emotional support. However it also highlighted the role played by the diabetes specialist nurse in positive care experiences.

2.8. Building on success

2.8.1. Progress has been made towards each element of the Action Plan in nearly every NHS Board. This is particularly the case with the roll-out of the Diabetic Retinopathy Screening programme across Scotland and the work towards reducing the incidence of emergencies in Type 1 diabetes. SCI-DC continues to develop as an integral part of diabetes care in Scotland.

2.8.2. Some Action Plan aims proved more challenging to achieve. Most diabetes MCNs have yet to undertake a needs analysis or review of services for minority ethnic communities. Only three NHS Boards currently offer structured education for those with Type 2 diabetes within 3 months of diagnosis, though a further nine are developing such programmes. Progress on access to psychological and emotional support for people with diabetes has also been a particular challenge. Additional funding over 2009/10 is targeted on making significant improvements in this area.

2.8.3. This section has set the scene with a brief overview of the main developments over the last 3 years, and the lessons which these hold for the way in which future developments should take place. The rest of the consultation document looks at how we can build on the work to date.

3. DEVELOPING HIGH QUALITY DIABETES CARE

3.1. Drivers of quality

3.1.1. Drivers of the development of high quality diabetes care include:

3.1.2. **Diabetes Clinical Standards** (NHS QIS). Clinical standards provide the basis for measuring local NHS performance against nationally agreed criteria. A review of the implementation of clinical standards was published in 2008.

3.1.3. **SIGN Diabetes Guideline** (Scottish Intercollegiate Guideline Network) SIGN provides an evidence base for clinical practice designed to reduce variations in practice and outcome. The SIGN guideline for diabetes, SIGN 55, is currently under revision, and is due to be published in the spring of next year.

3.1.4. **The Quality and Outcomes Framework (QOF) for General Practice and the Scottish Enhanced Services Programme (SESP)** for Primary and Community Care. The QOF and SESP incentivise primary care to focus on at-risk patients and improved outcomes for patients with diabetes. As from April 2009, the two target indicators for control of diabetes through HbA_{1c} measures have been changed to encourage even better control. In addition the QOF guidance for the foot assessment indicator now includes reference to foot risk stratification. Scottish practices have been achieving near maximum QOF points for diabetes indicators; and seven out of fourteen Health Boards have developed an enhanced service for diabetes care through the Scottish Enhanced Service Programme.

3.2. Managing improvement

3.2.1. Diabetes Managed Clinical Networks (MCNs) were established to bring together healthcare professionals, people with diabetes, unpaid carers and voluntary organisations to work across traditional boundaries in planning and delivering diabetes care. Their important role in the strategic planning of health services was recognised in the NHS QIS/Diabetes UK Scotland follow up report in March 2008.

3.2.2. The effectiveness of the diabetes MCNs depends on their ability to influence local planning and funding processes, and deliver nationally supported initiatives such as retinal screening, psychology support and quality assurance.

3.2.3. It is of particular importance that MCNs and local Community Health Partnerships (CHPs) work together effectively. CHPs have been set up across Scotland to provide a wide range of community based health services delivered in homes, health centres, clinics and schools. The participation of CHPs within MCNs is likely to promote an effective working relationship between the two.

3.2.4. It is for NHS Boards to determine the most effective means of developing the MCN model to meet local needs. For example, in one Board area, diabetes care is planned and coordinated through a Long Term Conditions MCN manager. This has the benefit of sharing learning between clinical areas as well as connecting more readily to national policy on long term conditions, for example, the Self Management Strategy, *Gaun yersel*'. It is important, however, that we do not lose sight of the specific care needs of people with diabetes.

3.2.5. The diabetes MCNs will remain central to the local planning process for patient-centred diabetes services and will have a key role in many areas including the integration of local clinical services, the development of redesigned pathways of care and staff education programmes. They will be the main agencies through which NHS Boards will meet the challenges set out in the revised Action Plan.

3.2.6. The Scottish Diabetes Group has a continued responsibility to bring together the diabetes MCN Lead Clinicians and Managers to ensure consistency of approach, and to identify themes of common interest in the working of the MCNs.

3.3. Supporting improvement

3.3.1. People with diabetes expect their care teams to communicate effectively, efficiently and with the relevant confidentiality safeguards in place. The necessity for high quality patient data in order to improve clinical management and service planning prompted the development of SCI-DC.

3.3.2. SCI-DC is a national programme of diabetes information management and technology development. It has now been rolled-out across all NHS Board areas and is linked to, and extracts relevant diabetes-related data from, all but seven of the GP Practices across Scotland and almost all Specialist Diabetes Clinics.

3.3.3. During 2008 the system was accessed on a total of 1,646,000 occasions by 2,621 different Health Service users from a very wide variety of different professional groups. SCI-DC can therefore now be considered an integral part of diabetes care in Scotland.

3.3.4. The SCI-DC team is currently working on giving people with diabetes access to their own diabetes related health data. Enabling access of this kind has been shown to improve people's ability to manage their own condition. This fits well with the approach outlined in *Better Health, Better Care* of encouraging people's active involvement in their own care. Further enhancements to the system during 2009 include:

- Specialist modules to support paediatric diabetes, podiatry, diabetes specialist nurses and dietetic teams;
- Linkage with biochemistry labs via SCI-Store;
- Linkage with Community Pharmacy;
- Automated 'back-population' of diabetes clinical data to GP systems; and
- Direct access by patients to their own diabetes-related health data.

3.3.5. The Scottish Government recognises the importance of SCI-DC's information sharing role, particularly in view of the multi-disciplinary nature of diabetes care. The Scottish Diabetes Group continues to monitor the progress made with SCI-DC and so ensure that the current momentum with the project is maintained.

ISSUES TO CONSIDER

- **How can we ensure that clinical standards are being maintained and improved?**
- **What is needed to ensure that the updated SIGN guideline drives forward service improvement?**
- **What more can be done to increase the effectiveness of the diabetes Managed Clinical Networks in developing local services.**

3.4. Focusing improvement

Type 1 Diabetes, Children and Families

3.4.1. The Short-Life Working Group (SLWG) on Type 1 diabetes has been set up to review services for people of all ages with Type 1 diabetes. It has identified a number of areas for particular consideration, including provision of education on diabetes, the diagnosis and management of people who develop diabetic ketoacidosis, intensification of insulin therapy, arrangements for transition from paediatric to adult clinics, and out-of-hours care. The SLWG will produce a draft report for consultation in autumn 2009.

3.4.2. The incidence of Type 1 diabetes in children has trebled over the last 30 years and is still increasing.

3.4.3. Studies by the Scottish Study Group for the Care of Diabetes in the Young indicate that overall glycaemic control in children under the age of fifteen is poor and only a small percentage achieve optimal blood glucose control.

3.4.4. Good control of diabetes in childhood and adolescence can reduce complications in later life but management is challenging and families need considerable support to optimise blood glucose control and quality of life at diagnosis and on a regular basis. Their needs change with time and are also affected by ethnic background, the level of psychosocial support available and issues around deprivation. Families need support at diagnosis and access to advice and guidance to ensure they do not feel overwhelmed by diabetes.

3.4.5. As children enter their teens, dealing with diabetes often becomes very difficult. At a time when their life is becoming full of all sorts of other responsibilities and worries like exams, dealing with parents and becoming sexually aware, they have the burden of an insistent medical condition requiring daily attention. Physiological changes during adolescence can lead to insulin resistance and problems with glucose control. Many become overwhelmed with the difficulties and drop out of diabetes clinics at this time, so extra effort is needed to keep in touch with them, and to provide a sympathetic environment which is sensitive to the needs of adolescents.

3.4.6. A survey carried out by Diabetes UK Scotland indicated that children with diabetes can face unnecessary problems at school, such as exclusion from school trips, being denied access to necessary snacks and issues around injections. Guidance on the Administration of Medicines in Schools, issued in 2001, is designed to support good practice at school and between schools, the health service and families. The guidance acknowledges that 'a child's experience of school can sometimes be interrupted by a medical condition. In these circumstances it is very important to ensure that their education should neither be interrupted nor curtailed by the need to take, or have medication administered whilst in school.'

3.4.7. While there is good practice in many schools across Scotland, work still needs to be done to ensure that no child with diabetes is, in any way, disadvantaged as a result of their diabetes. Equally, parents and families need to be supported to maintain working lives. Work is currently under way through the Long Term Conditions Alliance Scotland to develop policy in this area across long term conditions. At the same time the Short Life Working Group for Type 1 diabetes (SLWG) is currently looking at what work is needed to remove barriers and provide support in the school environment

3.4.8. One possible means for developing paediatric care currently under consideration is the development of a National Paediatric MCN for diabetes. This would complement the work of both the Scottish Diabetes Group and potentially provide a mechanism for delivering and implementing the recommendations of the Short Life Working Group on Type 1 diabetes.

ISSUES TO CONSIDER

- How can we continue to improve paediatric care and what are the priorities?
- What would be the role of a national Paediatric MCN for diabetes?
- How can transitional care arrangements be improved?
- How do we ensure that children with diabetes are supported at school?

3.5. Psychological and emotional support

3.5.1. Mental health problems occur frequently in diabetes; depression is the commonest disorder, but it is often unrecognised and untreated. It affects those with both Type 1 and Type 2 diabetes. Between 20 and 30% of people with diabetes will experience significant depression which is often associated with poor self-care. In adults with established Type 1 and Type 2 diabetes, the frequency of depression and anxiety is about twice as high as in the general population. Some studies suggest that depression and/or anxiety may affect up to 50% of young people with poorly controlled Type 1 diabetes. Depression may also be a risk factor for diabetes (especially Type 2), due to its effects upon diet, exercise and smoking/drinking.

3.5.2. The 2006 Action Plan recognised the strong association of depression among those with diabetes and the fact that psychological and emotional problems can represent a barrier to effective self management. Access to psychological support is also embedded in the NHS Quality Improvement Scotland clinical standards for diabetes services.

3.5.3. The current strategy developed by the Diabetes Psychology Working Group aims to implant psychological care within diabetes services, through training NHS staff to improve their skills in behaviour change and psychological support. Recent studies have shown that this approach can be effective in reducing HbA_{1c} levels while also allowing a larger number of people to benefit from psychological support than would otherwise be the case.

3.5.4. Training courses have been made available to all NHS Boards and all health care professionals involved in diabetes care. Staff have developed skills in communication with patients, and negotiation and helping patients to change important health behaviours.

3.5.5. Initial funding has been provided for a number of part-time chartered psychologist posts. Four are to be based within adult diabetes services and one employed within a paediatric diabetes service. The funding is open to all MCNs (nine of which have registered formal interest) and the early signs are that there is a great deal of interest across Scotland. All posts will last three years and there is an obligation on successful MCNs to make substantial efforts toward securing ongoing funding.

3.5.6. *Living Better* is a new initiative organised by the Royal College of General Practitioners which aims to improve the mental health and wellbeing of people with diabetes and coronary heart disease. It is funded by the Scottish Government and runs from January 2008 to November 2010. The project aims to improve the detection, assessment and management of depression, anxiety and stress, through the development and implementation of local care pathways. Its findings will be disseminated across Scotland.

ISSUES TO CONSIDER

- What further improvements can be made in the provision of psychological support for people with diabetes?
- How can these improvements be achieved?
- What outcomes would indicate acceptable progress in this area?

3.6. Diabetes-related hospital admissions and inpatient care

3.6.1. People with diabetes stay an extra two to three days in hospital compared to those with other conditions and around 10% of people in hospital, at any one time, have diabetes. Interventions such as foot care in the community and additional inpatient support can reduce admissions and bed occupancy for people with this condition.

3.6.2. The HEAT (Health Improvement, Efficiency, Access, Treatment) targets reflect the priorities, objectives and measures agreed as part of local delivery plans with each NHS Board. The HEAT target most relevant to diabetes is T6: 'to achieve agreed reductions in the rates of hospital admissions and bed days of patients with primary diagnosis of COPD, Asthma, Diabetes or CHD, from 2006-07 to 2010-11'.

3.6.3. Progress towards achieving this target has been advanced with the introduction of a national protocol for the management of adolescents and adults with diabetic ketoacidosis (DKA) which is currently in use in several hospitals across Scotland. The Scottish Diabetes Group's Type 1 working group is considering further audits to measure the incidence of DKA as well as further actions to promote awareness of DKA among both the public and health care professionals. There is also evidence to suggest that early supported discharge by a team including specialist nurses can be very effective in reducing bed days for diabetes.

ISSUES TO CONSIDER

- How can we further reduce the numbers of diabetes-related hospital admissions; and what should the priorities be?
- How can we measure in-patient activity for people with diabetes more effectively?
- How can we improve the quality of in-patient care for people with diabetes?

3.7. Black and Minority Ethnic Communities

3.7.1. UK South Asians are about four times more likely to develop diabetes than their peers from other ethnic groups, while the black population is twice as likely to develop the condition. Improving access to diabetes care for these high risk groups has therefore been a vital component of our diabetes strategy.

3.7.2. Some NHS Boards have yet to complete a needs assessment of their population to identify disadvantaged groups and data collection on ethnicity has reached 50% rather than the 80% target.

3.7.3. The Scottish Diabetes Group's Diabetes Minority Ethnic Group (DMEG) has recently been re-formed with the aim of improving outcomes for people with diabetes from minority ethnic communities. DMEG aims to prioritise prevention, early detection, improving access to culturally appropriate diabetes care, self management and carer education for both Type 1 and Type 2 Diabetes. Two subgroups, 'Education and Training' and 'Information and Resources' have been established. A wider Stakeholder Network involving the minority ethnic voluntary sector, MCNs and other health care professionals will be set up to share and disseminate good practice. DMEG is therefore now in a position to play a significant role in ensuring that the Action Plan's focus on improving services in this area continues.

3.7.4. The Prevention of Diabetes and Obesity in South Asians (PODOSA) study, funded by the National Prevention Research Initiative and supported by a range of government and charity funders, led by the Medical Research Council, is testing ways to prevent diabetes. It is being carried out by a research team from Edinburgh and Glasgow Universities. People were recruited to the study during 2007 and 2008 and will be involved for 3 years.

3.7.5. In the PODOSA study, a team of dietitians will work with people at high risk of developing diabetes to encourage weight loss and increased physical activity, in order to find out if this approach can prevent or delay the onset of diabetes. Dietitians will also involve other members of the family to help motivate the person at high risk. People's diet and level of physical exercise will be examined, with the aim of achieving a reduction in blood glucose levels, weight loss, and waist and a reduced hip size. So far, over 1,000 people have been screened, 8% of whom have been diagnosed with diabetes and a further 16% with Impaired Glucose Tolerance or Impaired Fasting Glucose. This means that the body does not use glucose properly, which contributes to high blood sugar levels.

3.7.6. The diabetes MCNs have taken steps to ensure that all healthcare professionals caring for people with diabetes have access to information about locally available health improvement resources such as smoking-cessation services, Counterweight programmes, sport and leisure facilities, and healthy eating advice and referral options. They need feedback from central initiatives so that lessons learned from preventive community medicine initiatives, such as *Keep Well*, are applied in the context of diabetes. The Action Plan will reinforce the role that the diabetes MCNs can play in promoting the prevention of Type 2 diabetes.

3.7.7. Over the past three years, there have been several initiatives focused on diabetes in black and minority ethnic communities:

- 'Focus on Diabetes' A guide to working with black and minority ethnic communities in Scotland living with long term conditions (Diabetes UK and NRCEMH, 2007);
- Evaluation of diabetes services for Black and Minority Ethnic communities in Scotland – results of a survey of Diabetes Managed Clinical Networks, (2006); and
- Structured Diabetes Education Packs for South Asian and Chinese Communities (NHS Greater Glasgow and NRCEMH) (To be launched in September 2009).

ISSUES TO CONSIDER

- **How can we further improve services and the experience of care for people with diabetes from minority ethnic communities?**
- **What would indicate acceptable progress in this area?**

3.8. Diabetic Foot Care

3.8.1. A Diabetes Foot Action Group was established in 2007 with the following goals:

- Develop consistent patient information nationally;
- Develop educational tools for use by all health-care staff;
- Identify specialist foot services available across Scotland;
- Support the development of Local 'Foot' Networks;
- Record foot risk stratification (75% of all patients by 2009); and
- Develop accredited training programmes to recognise specialist skills.

3.8.2. Six nationally agreed patient education leaflets, a booklet on foot-care and a DVD for professional education for patients have been developed. All of these educational tools have been circulated nationally and are, or will be, web-available.

3.8.3. The launch of the National Foot Screening Programme at the Scottish Parliament in 2008 has been followed up by a number of ongoing road shows across Scotland, to promote not only the educational materials, but also supporting local foot-networks, rolling out foot risk screening and the other general aims of the Diabetes Action Plan. The number of people with diabetes who have undergone a SCI-DC foot risk stratification rose from 25% in August 2007 to 45% by September 2008. This demonstrates a significant increase, especially when considering a number of IT difficulties which are currently being addressed.

3.8.4. A survey has been undertaken to identify what specialist foot services are available across Scotland. It has been surprisingly difficult to define a 'Multidisciplinary Foot Clinic', but a consensus has been reached, which has enabled benchmarking of specialist foot services. This has led to a short document defining a desirable service specification. Initial discussions are under way with NHS Quality Improvement Scotland (NHS QIS) to determine if this document and the forthcoming SIGN guideline may underpin a NHS QIS service specification for high quality diabetic foot services.

3.8.5. Further work identified key contact points for specialist foot services in each diabetes MCN. The aim of establishing such a register is to share it with primary care out of hours services, A&E departments and possibly NHS 24, so that patients can be directed by out of hours services to specialist diabetes foot care services which normally operate during routine working hours.

3.8.6. This work is linked to the appropriate NHS QIS clinical standard on diabetes, which states: 'All people with diabetes who have identified associated foot problems are referred for specialist assessment and, where necessary, treatment.'

ISSUES TO CONSIDER

- How can we continue to improve footcare for people with diabetes?
- What outcomes would indicate acceptable progress in this area?

3.9. Retinopathy screening

3.9.1. Diabetic retinopathy is the largest single cause of blindness and visual impairment amongst people of working age. It is a common complication of diabetes that affects the blood vessels behind the eye. The longer a person has diabetes, the greater the likelihood of developing diabetic retinopathy. In its early stages, diabetic retinopathy is symptom-free. Early detection of sight threatening retinopathy and treatment by laser therapy has been shown to be effective in preventing visual impairment.

3.9.2. Since the publication of the Diabetes Action Plan in 2006 each NHS Board in Scotland has set up a Diabetic Retinopathy Screening Service, based on a national standard of digital retinal photography. These services are coordinated by the Diabetic Retinopathy Screening Collaborative (DRSC). There has been significant progress since 2006 with some Boards achieving the target of 80% of the eligible population screened within the twelve month period to April 2008. The Diabetic Retinopathy Screening (DRS) programme in Scotland is very dependent on information technology and, in particular, the interface to the SCI-DC diabetes database.

3.9.3. Implementation of the retinopathy programme has presented a number of challenges which have meant the programme has not been established as quickly as originally envisaged. Nevertheless, the retinopathy screening programme in Scotland, with a single screening system electronically linked to a national diabetes register is, arguably, the most advanced in the world. The 2008 survey found that 71.9% of patients had a record of eye screening in the previous 15 months.

3.9.4. It is uncertain if all patients who already attend eye clinics are included in the screening data. This infers that the number of people getting their eyes screened might actually be higher than the numbers recorded. More exploratory work on data accuracy needs to be carried out.

3.9.5. The Scottish Government has now provided a grant to optometrists to purchase digital cameras, and from April 2009 optometrists are obliged to offer retinal photography to all people aged 60 and over, whether they have diabetes or not. Optometrists and the DRS Programme need to work together to enable people with diabetes to benefit from a cohesive and first class service. Patients are strongly encouraged to attend their DRS appointment even if they have had retinal photography at their optometric examination. It is equally important that patients who have had a DRS episode are strongly encouraged to attend their optometric examination, especially as people with diabetes are more prone to other eye conditions which may not be detected in the DRS programme. A pilot study of optometrist image capture is being undertaken to inform possible future involvement of community optometrists in DRS and determine the benefits which increased partnership working would bring to patients.

3.9.6. In 2007/08, a joint campaign between Diabetes UK Scotland and RNIB Scotland sought to raise awareness of the availability of diabetic retinopathy screening in communities across Scotland. Funded by the Scottish Diabetes Group and other agencies, the campaign organised a roadshow, which travelled to NHS Board areas including Orkney, Shetland and the Western Isles. Venues included a Farmers' Market in Inverness and Gala Bingo in Maryhill, Glasgow.

ISSUES TO CONSIDER

- How can we continue to improve retinopathy screening and eye care for people with diabetes?

3.10. Structured Education

3.10.1. Education is a cornerstone of good diabetes care. The NHS QIS/Diabetes UK Scotland overview report on diabetes care published in March 2008 noted that 12 of the 14 NHS Boards had well-established systems in place for the provision of some form of education session to newly diagnosed patients.

3.10.2. The provision of structured education calls for investment of time and human resources, either to train educators or to obtain cover while existing staff cascade training to other staff. Implementation of educational programmes can be challenging for the diabetes Managed Clinical Networks, since regular structured education programmes may not have an obvious source of funding. In addition, some clinical staff may not have the expertise to deliver group education and there may be limited staff time to attend training courses in education techniques. These educational activities are however essential to basic diabetes care. The following are examples of evidence based structured education programmes available in Scotland.

3.10.3. DAFNE (Dose Adjusted For Normal Eating) is a structured education programme for people with Type 1 diabetes that involves a 5-day training course delivered to groups of 6-8 participants that covers topics such as carbohydrate estimation, blood glucose monitoring, insulin regimens, hypos, illness and exercise. DAFNE courses are currently delivered in NHS Dumfries & Galloway, Grampian, Greater Glasgow & Clyde, Lanarkshire and Lothian.

3.10.4. DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) is a structured education programme for those with Type 2 diabetes. Studies have shown this approach to be effective at encouraging weight loss, smoking cessation and in helping to decrease depression scores; though there is less evidence to show that it decreases HbA_{1c} levels. DESMOND courses are delivered in Greater Glasgow, Dumfries and Galloway and parts of Lothian.

3.10.5. The X-PERT programme is also a structured patient education programme for people with Type 2 diabetes. It shows an increase in patient empowerment, improvement in HbA_{1c} and lipid profile, weight loss and reduction in weight circumference, all maintained at one year. X-PERT is delivered in Lanarkshire.

3.10.6. Funding from the Scottish Diabetes Group has supported a project undertaken by the Scottish Study Group for the Care of Diabetes in the Young entitled 'Improving services for people with Type 1 diabetes'. One of the project's aims is to develop a standardised set of educational tools and programmes for Type 1 diabetes, to promote consistency of approach across the country. The project's first task was to conduct a survey of current educational strategies. An interim report, giving an overview of the education services currently available to people with Type 1 diabetes, was produced in June 2008. This found that although patients were receiving information, they did not necessarily understand or know how to apply it.

3.10.7. A further aim of this project is the development of a Scottish Diabetes Education Network, the first meeting of which took place towards the end of 2008. Part of the Network's role is to enable diabetes educators to develop appropriate resources and national standards for diabetes education delivery. It aims to 'better utilise, share and benefit from colleagues' experiences locally and develop appropriate resources and national standards for diabetes education'. It also gives diabetes educators the opportunity to organise and deliver throughout Scotland local and regional meetings which will address issues pertinent to diabetes education practice. Diabetes UK Scotland is one of the driving forces of the Network.

3.10.8. SIGN has established a Lifestyle group as part of their review of its Diabetes Guideline. This group is considering the evidence on structured education.

3.10.9. Consideration will need to be given to the most effective way of increasing the provision of structured education programmes. Added attention will need to be focused on the information and educational needs of those who have had diabetes for some time, as well as those newly-diagnosed. It is also important that information is provided in a way that does not widen health inequalities. Delivery of structured education needs to be rigorously monitored in terms of quality assurance, and training and accrediting the trainers.

3.10.10. There is currently no evaluated, structured paediatric or adolescent education programme in the UK although two are in preparation; what is available is unstructured and some educators have limited formal training in education.

ISSUES TO CONSIDER

- **What outcome would indicate progress in the area of structured education?**
- **How can we improve access?**
- **How can we ensure quality across Scotland?**

3.11. Professional education

3.11.1. The Diabetes Education Advisory Group (DEAG) has overseen a number of projects and initiatives relevant to the Diabetes Action Plan over the last year, including the development of a Scotland wide strategy for professional education. DEAG has also been working with the Scottish Diabetes Industry Alliance to re-establish the 'Diabetes in Scotland' web site www.diabetesinscotland/org.uk and to provide a database of current educational courses and activity in Scotland. This is now complete and links into other related educational sites such as the long term conditions educational resource and the eLibrary diabetes portal.

3.11.2. A subgroup of the DEAG worked with Doctors Online Training Scheme (DOTS) and accessed input from a multi-disciplinary group, to form an online diabetes training course for junior doctors. This course has potential benefits to other clinical and nursing staff and opportunities for these personnel to access the information are being explored.

3.11.3. Given the further areas of diabetes inpatient management which need to be addressed, it is proposed to form an 'Inpatient Management Group' which will report to the DEAG and advise on educational needs for staff to ensure patient confidence during any inpatient events. (See 3.6)

3.11.4. The diabetes MCNs are responsible for co-ordinating educational and training initiatives for staff to ensure professionals are equipped to deliver the range of clinical services across the Network both in the community and in specialist practice. This can range from the delivery of highly specialist services such as treatment with Continuous Subcutaneous Insulin Infusion (CSII) to the management of diabetes by non-specialist staff in care homes. It will include expertise in the delivery of high quality patient centred individual and group educational programmes.

ISSUES TO CONSIDER

- How can we ensure access to appropriate education for all health care professionals and health care workers in Scotland?
- What outcomes could assess this?

3.12. Research

3.12.1. The Scottish Diabetes Research Network (SDRN), funded by the Chief Scientist Office (CSO), conducts an annual audit of all diabetes clinical research in Scotland. The volume of diabetes research continues to increase and in 2008, 80 academic studies and 37 commercially funded clinical studies were carried out in Scotland. Just over 20,000 participants were involved, including 15,500 people who were recruited to the Wellcome Trust funded case-control study aimed to identify key genes that can predispose to diabetes. CSO is currently supporting 16 diabetes projects at a cost of £2.6m in addition to key genetics projects such as Generation Scotland (£8m) and Scottish island isolate of Orkney project (~£1m), both of which measure quantitative traits related to diabetes. The Network currently receives £340,000 a year and will receive over £1.8m of funding over the next three years to continue to:

- Establish an integrated diabetes research infrastructure between the four major academic centres in Scotland and associated Managed Clinical Networks;
- Increase the volume of high quality commercial and academic clinical trials and increase recruitment throughout Scotland;
- Provide a platform for high quality, unintrusive epidemiology on a national level; and
- Increase awareness and opportunities for patients to be recruited to clinical trials.

ISSUES TO CONSIDER

- What should future research priorities be?
- How can we increase public involvement in research?

3.13. Out-of-Hours and Remote and Rural Services

3.13.1. The Type 1 Diabetes Short Life Working Group and the diabetes Managed Clinical Networks have explored means to improve access to out-of-hours diabetes advice for families with children with diabetes in order to reduce the number of unplanned admissions for metabolic emergencies. DiabNet was established to provide consistent, coordinated, high quality care and support for children with diabetes and their families across NHS Tayside, Fife and Forth Valley. Better cross-border communication and practice has been developed, new clinics and support groups have been established and a specialist 24-hour helpline is available to families.

3.13.2. Recent discussions have taken place between the Type 1 Short Life Working Group and NHS 24 on the subject of further improving their diabetes out-of-hours service, and the consensus is that this represents a viable alternative to rolling out the DiabNet scheme further.

3.13.3. Remote and rural areas pose specific challenges to the delivery of care. Telehealth can help diabetes services overcome these obstacles, by allowing clinicians to consult with patients remotely. At the moment live video conference clinics are available for people with diabetes in Orkney. This includes links to a computer for patient monitor readings. These are supported locally by nursing staff and a consultant based in Aberdeen. Telehealth can also allow GPs to consult with specialists thereby reducing the need for referrals.

3.13.4. Telehealth may also have a role to play in supporting self management. The TeleScot randomised control trial incorporating home monitoring of patients with diabetes is due to start later this year in NHS Lothian (funded by the Chief Scientist Office and involving around 300 patients). The small trials that have been carried out are very positive but need to be repeated in the UK and in large enough numbers to have the power to demonstrate effectiveness.

ISSUES TO CONSIDER

- **What can be done to ensure out-of-hours care services are equitable across Scotland?**

3.14. Pregnancy

3.14.1. Type 1 diabetes mellitus is a high risk state for both the woman and her foetus because of increased risks of spontaneous abortion, ketoacidosis, severe hypoglycaemia, pre-eclampsia, premature labour, polyhydramnios, late intrauterine death, foetal distress, obstructed labour and congenital malformation. Infants of mothers with diabetes need careful monitoring after birth.

3.14.2. Previous hospital based audits in Scotland and England and Wales have highlighted the continuing challenges of management of pregnancy in women with diabetes. In Scotland paper audits were held in 1998/1999 and in 2003. These audits reported an increase in birth weight, rates of caesarean section, congenital anomalies and perinatal mortality relative to the background population.

3.14.3. Type 2 diabetes is less common than Type 1 diabetes during the reproductive years but management prior to and during pregnancy should follow the same intensive programme of metabolic, obstetric and neonatal supervision.

3.14.4. An optimal outcome may be obtained in diabetic pregnancy if excellent glycaemic control is achieved before and during pregnancy. This requires that pregnancy should be planned. Good contraceptive advice and pre-pregnancy counselling are thus recommended. An experienced multiprofessional team led by a named obstetrician and physician should provide comprehensive maternity care prior to and during pregnancy.

ISSUES TO CONSIDER

- What initiatives could further improve outcomes of pregnancy in women with diabetes?

3.15. Insulin pump therapy

3.15.1. Continuous Subcutaneous Insulin Infusion (CSII or pump therapy) can lead to significant improvement in glycaemic control and quality of life for some people with Type 1 diabetes. The safe and effective use of insulin pumps requires a motivated individual to monitor blood glucose levels on a regular basis, as well as all aspects of their diabetes.

3.15.2. Education, and regular support from a competent diabetes team, are therefore critical for all those using insulin pumps. The current guidance outlined in NICE Technology Appraisal 151 (July 2008) has been validated by NHS QIS. It says that insulin pump therapy should be considered as an option for adults and children over 12 years when multiple dose insulin therapy has failed. Insulin pump therapy is also recommended as a possible treatment for children under 12 with Type 1 diabetes if treatment with multiple daily injections is not practical. These criteria will be reflected in the template for insulin strategies being developed by the Scottish Diabetes Group's Short Life Working Group on Type 1 Diabetes, and may need modification after publication of the revised SIGN Guideline on diabetes.

3.15.3. In 2008, there were at least 416 people in Scotland on insulin pumps, equating to nearly 1.5% of the Type 1 population, in line with previous NICE guidance. The revised advice, however, could mean up to 3,750 people in Scotland on a pump.

3.15.4. Prevalence of insulin pump usage varies between NHS Boards. The Scottish Diabetes Group aims to address this variation through supporting actions such as the Insulin Pump Education Day that took place in May 2009. This brought together teams from NHS Boards across Scotland to discuss current CSII arrangements and future developments. A patient-led Insulin Pump Awareness Group is in the process of forming in the west of Scotland. The group, which is being supported by Diabetes UK Scotland, aims to assist people with diabetes who may want to use pump therapy.

3.15.5. Decisions surrounding the provision of insulin pumps should be evidence based and take account of patient choice as well as the availability of alternative therapies that can provide equally successful outcomes for patients. NHS QIS will work on an impact assessment looking at the revised SIGN guideline on diabetes, and this should provide further evidence to support and guide judgements surrounding the use of insulin pumps.

ISSUES TO CONSIDER

- What further steps should be taken to increase the appropriate availability of insulin pumps?
- What support structures need to be in place to ensure that insulin pumps therapy is fully effective?

3.16. Care Homes

3.16.1. National Care Standards for residential care include the right to make informed choices and the right to safety and security in health and wellbeing. People with diabetes living in care homes need supportive diabetes care to ensure, for example, that they are able to access good podiatry care and that they can make choices about their care, including self management. Their care workers also need to have an understanding of diabetes management.

3.16.2. Over the past few years, Diabetes UK Scotland has successfully organised diabetes study days for care home and other social work staff. Collaboration with those responsible for training programmes for staff in care homes could lead to the development of programmes to improve diabetes knowledge and skills of staff and support residents. Innovative mechanisms would be required to deliver these courses at a local level throughout Scotland.

3.16.3. Similar opportunities could be made available to other groups of staff in non-NHS locations such as prisons, schools and workplaces.

ISSUES TO CONSIDER

- What developments could improve diabetes care for those in care (including custodial) settings?

3.17 Renal Disease

ISSUES TO CONSIDER

- Kidney disease is an important complication of diabetes. What more can be done to prevent kidney disease in people with diabetes?

4. PUTTING PATIENTS AT THE CENTRE

4.1. Patient Focus

4.1.1. In today's NHS, the views of patients and carers have, in principle, the same weight as clinical standards.

4.1.2. The Scottish Health Council has been reformed to help improve the way that people are involved in decisions about health services.

4.1.3. The Patient Experience Programme, *Better Together*, was established to drive service improvement through patient feedback.

4.1.4. Plans for Patients' Rights legislation affirm a fundamental shift in the relationship between patients and the NHS. Supporting people with diabetes to take personal control of the management of their diabetes is key to a successful action plan.

4.2. Support for self management

4.2.1. According to Diabetes UK, self management is achieved through 'provision of information, structured and ongoing education and psychological and emotional support. People with diabetes need the knowledge, skills and motivation to assess their risks, to understand what they will gain from changing their behaviour or lifestyle and to act on that understanding by engaging in appropriate behaviours.'

4.2.2. People with Type 2 diabetes who become regularly physically active can potentially gain several improvements in health including better glycaemic control, fewer diabetes complications and a better quality of life. A more active population of people with Type 2 diabetes could substantially reduce healthcare burden and expenditure. Given the current epidemic nature of Type 2 diabetes and the extensive benefits of physical activity for the management of Type 2 diabetes, physical activity, alongside improved diet, should be a major priority for people with diabetes and their diabetes care team.

4.2.3. The Long Term Conditions Alliance Scotland (LTCAS), supported by the Scottish Government, has developed the Scottish strategy for self management, *Gaun Yersel*. The strategy states:

- Self management is a person-centred approach in which the individual is empowered and has ownership over the management of their life and conditions;
- The role of health and social care professionals, services and treatment is to support the person's journey towards living well in the presence or absence of systems; and
- The approach must be properly resourced.

4.2.4. The Scottish Government has allocated £2m in 2009-2010 and £2m in 2010-2011 to the LTCAS to operate a Self Management Fund. The fund is open to voluntary sector organisations, possibly in partnership with statutory agencies, and it provides an opportunity to develop new initiatives over the next two years which will support people living with diabetes to self care.

ISSUES TO CONSIDER

- What outcomes would indicate acceptable progress in improving support for self management for people with diabetes?
- In what ways should a future diabetes action plan build on the Self Management Strategy for long term conditions?
- What kind of diabetes initiatives would you like to see funded by the Self Management Fund?

4.3. Supporting carers to support self management

4.3.1. There are 660,000 unpaid carers in Scotland and, of these, 110,000 provide 50 hours of care or more each week. Carers are key partners in the provision of care and as such should be involved in individual care planning, policy development and service planning.

4.3.2. Diabetes impacts on unpaid carers in two ways. There are carers who look after others who have diabetes, for example, parents of children with Type 1 diabetes, or people who look after someone with diabetes-related complications. There are also carers who have diabetes and need to deal with looking after their own health while caring for another. On both fronts there is a clear need to support carers in relation to self management – through information, education and personal support.

4.3.3. Specific consideration also needs to be given to young carers, a fifth of whom receive no formal support. Although diabetes may not be the primary condition in relation to their caring responsibilities, diabetes information and support are still vital.

4.3.4. Since 2005, Scottish Ministers require all NHS Boards to prepare and submit for approval a Carer Information Strategy. Strategies need to identify information needs of carers as well as their training needs.

4.3.5. Carer Information Strategies are mechanisms at NHS Board level to help deliver diabetes-related information with a view to better supporting unpaid carers.

ISSUES TO CONSIDER

- What outcomes would indicate acceptable progress in support for self management for carers?

4.4. Self management and vulnerable groups

4.4.1. Some patients have difficulty in accessing the full range of diabetes services, including support for self management. According to the Lothian diabetes MCN Equity Audit Report in 2008, there is greater risk of diabetes among people with learning disabilities, in part due to lifestyle factors. Response to the needs of those with learning disabilities and other vulnerable groups is varied in the NHS. Lothian, for example, has produced a healthy eating toolkit aimed at carers. In England, the Northamptonshire Teaching Primary Care Trust has developed a structured education package based on the principles of self management. The course uses easy words, pictures and other visual aids and participants can bring a carer or supporter. Other initiatives include learning workshops for unpaid carers, accessible information packs and DVD-resources.

ISSUES TO CONSIDER

- What more should be done to support people with diabetes who are particularly vulnerable, for example, people with learning disabilities, to self manage more effectively?

4.5. Involvement and participation

4.5.1. The effective participation of people with diabetes is seen as one of the key ways in which services will improve and the effectiveness of the Managed Clinical Networks will be strengthened over the next three years. It is essential to make sure that people with diabetes get the training and support they need to make the most effective contribution to diabetes service planning.

4.5.2. The Diabetes Care Focus Group brings together people with diabetes from across Scotland to provide advice to the Scottish Diabetes Group reflecting their experience of diabetes care. It met for the first time in March 2008, and its current objectives include:

- Widespread availability of Structured Education Programmes for people across Scotland;
- Effective networking to share the best practice and development across the patient community;
- Active patient involvement in the Scottish Diabetes Group's sub-groups;
- Extensive use of the patient website www.mydiabetesmyway.scot.nhs.uk, the NHSScotland interactive diabetes website to help support people who have diabetes, their families and their friends. It has leaflets, videos, educational tools and games containing information about diabetes; and
- Review of diabetes peer support initiatives.

4.5.3. Scottish Government funding given to Diabetes UK Scotland to support involvement of patients and carers in the diabetes Managed Clinical Networks has resulted in the development of the Diabetes Voices programme. This programme will continue to be rolled out over the next three years and, where necessary, adapted to target specific groups and maximise geographical coverage. At the same time, Diabetes UK Scotland continues to develop and support its individual and group membership base – 11,000 members and 40 voluntary groups – as an informed audience ready to respond to and take part in relevant activities.

ISSUES TO CONSIDER

- **How do we ensure that people with diabetes and their carers are able to participate in local service planning?**

4.6. Peer support

4.6.1. The Diabetes Care Focus Group will continue to explore the most effective way to provide peer support for people with diabetes particularly the newly diagnosed. This is an important part of self management involving people living with diabetes supporting others, at key stages of living with the condition; a review of the Buddy Service is due to get under way in June 2009. Agreement on the way forward for the service will form part of the new Action Plan.

ISSUES TO CONSIDER

- **What indicators or outcomes would indicate acceptable progress in self management for people with diabetes and their carers?**

5. BETTER PREVENTION OF TYPE 2 DIABETES, EARLIER DETECTION OF THE DISEASE AND PREVENTING COMPLICATIONS

5.1. PREVENTION

5.1.1. Much of Type 2 diabetes can be prevented. This is one of the single biggest public health challenges facing Scotland, not least because of the obesity epidemic. It is therefore essential that we develop the best possible means of preventing or delaying the onset of Type 2 diabetes and detecting diabetes as early as possible, to prevent complications. This section of the consultation document looks at possible ways of doing so.

5.1.2. Type 2 diabetes mellitus is the most common type of diabetes and accounts for around 86.7% of cases in Scotland. Type 2 diabetes is commoner in older, less active and overweight individuals but genes have an important role in the development of diabetes and many people with Type 2 diabetes have a family history of the condition. After many years of frustratingly limited success, the way in which genes influence the development of Type 2 diabetes is finally being uncovered. Unlike in rare forms of diabetes such as maturity onset diabetes of the young (MODY), there are a number of different genetic influences which, along with the environmental factors mentioned above, combine to determine if an individual is likely to develop diabetes.

5.1.3. The *International Diabetes Federation: a consensus on Type 2 diabetes prevention* concludes that, in planning national measures for the prevention of Type 2 diabetes, people at high risk of developing Type 2 diabetes together with the entire population should be targeted simultaneously with lifestyle modification as the primary goal.

5.2. Promoting healthy lifestyles

5.2.1. The Scottish Diabetes survey found over 80% of people with Type 2 diabetes are overweight or obese.¹ Population-level interventions to stabilise and then reverse obesity trends are probably the single biggest factor in reducing the incidence of Type 2 diabetes.

5.2.2. In June 2008, the Scottish Government published *Healthy Eating, Active Living: An action plan* to improve diet, increase physical activity and tackle obesity (2008/2011). It outlines plans to invest £56m in initiatives set out in the three year plan which are aimed at supporting people to make healthier choices in what they eat, to build more physical activity into their everyday lives and to maintain or achieve a healthy weight. The actions identified in the plan take a themed approach aimed at early years, schools and school age children, adults and workplaces, older people and communities. The Action Plan also sets out the Government's intention to develop a long-term strategy to tackle the rising obesity epidemic.

5.2.3. The Scottish Government is committed to finding innovative ways to tackle diabetes prevention. For example, the Chief Scientist Office recently contributed £200,000 towards the cost of a research project led by Professor Sandra MacRury, clinical professor at the University of the Highlands and Islands Department of Diabetes and Cardiovascular Science in Inverness, looking at the immediate effects of an oat-rich diet. The aim is to develop new dietary plans which could improve diabetes control, delay the need for people with Type 2 diabetes to start tablets or insulin to control their blood sugar, and potentially reduce the risk of some of the complications of diabetes

5.2.4. The Scottish Government aims to increase and maintain the proportion of physically active people in Scotland, and is setting targets to achieve 50% of adults aged over 16 and 80% of all children aged 16 and under who meet the minimum recommended levels of physical activity by 2022. This is being taken forward by education and awareness programmes such as *Free to Dance* and *Take Life On*.

5.2.5. A number of Scottish National Prevention Research Initiative (NPRI) projects are relevant to the prevention of diabetes. For example, there are current projects focusing on bodyweight and lifestyle management programmes; food purchasing behaviour; access to physical activity opportunities; the contribution of neighbourhood environments to ethnic differences in obesity, physical activity and diet; and economic appraisal of the choice and targeting of lifestyle interventions in deprived populations. In addition, NPRI is now in its third call for proposals with a further £12m available to support cross-disciplinary, translational research to develop or test interventions that have the potential to make a major impact on health at the population level.

5.3. Anticipatory Care

5.3.1. *Better Health, Better Care* committed the Scottish Government to developing a programme of 'Life Begins' checks. This programme will invite people reaching the age of 40 to conduct a web based self assessment through which they can identify which, if any, personal, family and lifestyle issues could pose a risk for their future health and well being. Where needed, people will be signposted to sources of help and given the option of a telephone consultation with a health adviser. There will be a facility for practices to be informed of the outcome of the self assessment, with patient consent.

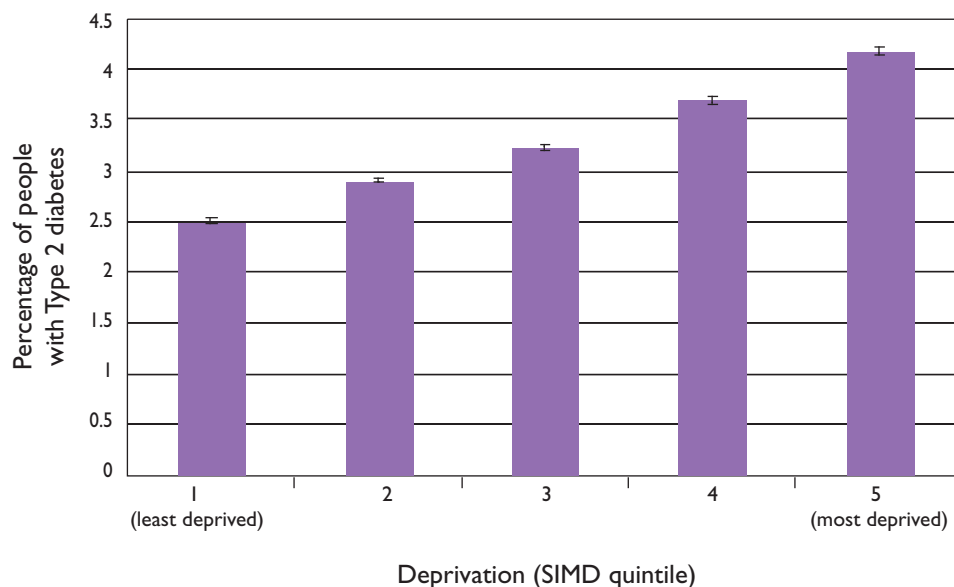
5.3.2. As regards diabetes, this means that those at risk of Type 2 diabetes due to family history or because of obesity/lifestyle will have this drawn to their attention at age 40 and will be advised as to how they can reduce their risk and/or be tested for unsuspected diabetes. NHS 24 is currently engaged in developing a robust online self assessment programme, complemented by telephone based assistance that would fulfil this commitment.

5.4. TACKLING HEALTH INEQUALITIES

5.4.1. The Scottish Diabetes Survey and a study led by the University of Edinburgh (Wild *et al.*, 2008) has demonstrated a strong relationship between deprivation and Type 2 diabetes incidence. The results of future analyses of these data will be useful to the diabetes Managed Clinical Networks in reviewing and planning services, as well as to health promotion teams in assessing and planning primary and secondary prevention of diabetes and cardiovascular disease. This growing evidence reinforces the importance of tackling inequalities as highlighted by *Better Health, Better Care*:

Poor mental and physical health is both a cause and consequence of social, economic and environmental inequalities

Figure 2: Data for Scotland 2008 – Type 2 Diabetes and Deprivation



SIMD = Scottish Index of Multiple Deprivation

5.4.2. The Scottish Ministerial Task Force on Health Inequalities produced a report, *Equally Well*, that recommended the Government commitment to health checks for all at age 40 should be implemented in ways that build on the *Keep Well* programme, which targets Cardiovascular disease (CVD) including diabetes. *Equally Well* highlights *Keep Well* health checks (see paragraph 5.6.1). These plans are now being taken forward by the Scottish Government, NHS Health Scotland and NHS Boards.

5.4.3. *Equally Well* also links people living in deprived areas with chronic health conditions associated with obesity, including Type 2 diabetes. Recommendation 29 states that the Government, NHS Boards and other public sector organisations should take specific steps to encourage the use and enjoyment of greenspace by all, with a view to improving health. Public sector organisations should provide materials, resources and training and evaluation of specific initiatives, such as the prescription of 'greenspace use' by GPs and clinical practitioners.

5.5. Cardiovascular disease

5.5.1. Cardiovascular disease is the major cause of death in diabetes, accounting for some 50% of all diabetes fatalities, and significant levels of disability. Recent collaborative work between the British Heart Foundation, Chest, Heart & Stroke Scotland, Diabetes UK Scotland and the Stroke Association has resulted in the emergence of an informal voluntary sector alliance around cardiovascular issues.

5.5.2. SIGN 97 on risk estimation and prevention of cardiovascular disease is directly relevant to diabetes. It has now been reflected in NHS QIS's draft clinical standards for Coronary Heart Disease (CHD). Among people with diabetes, mortality from heart disease is increased by 300%, and heart failure is up to four times as likely. Effective treatment leads to a reduction in heart failure of over 50%. Stroke risk is up to four times as likely and effective treatment reduces strokes by more than a third. It is therefore essential to make a link between this Action Plan and the revised Heart Disease and Stroke Action Plan. One way of achieving this link would be through the stroke, diabetes and cardiac MCNs working more closely together.

5.5.3. Nearly 1 in 5 people with diabetes are recorded as current smokers. The Scottish Government has committed £33m over the next three years to NHS smoking cessation services and this year invested £3m in a national smoking cessation pharmacy scheme. The Scottish Government is now focussing on preventing children and young people from starting to smoke in the first place. *Scotland's future is smoke-free, a smoking prevention action plan* was published in May 2008. Backed by £9m over three years, the plan has led to the Tobacco and Primary Medical Services (Scotland) Bill, which will ban the display of tobacco products and the sale of tobacco from vending machines and will introduce a tobacco retailers registration scheme, which could see retailers lose the right to sell tobacco if they continually flout tobacco sales legislation, such as selling tobacco to under-18s.

5.6. Keep Well Programme and ASSIGN

5.6.1. The *Keep Well* programme is targeted at people living in deprived communities at high risk of developing cardiovascular disease (CVD), including diabetes. It undertakes screening of 45-64 year olds living within these communities and aims to shift the focus across the NHS and supporting services from treatment of illness to prevention. By early identification of the risk factors associated with CVD, individuals will be referred on to further services, or prescribed drugs, including statins, to reduce their risk of later poor health outcomes. So far, at least 35,000 people have undergone this assessment. The learning and best practice generated by the programme will be disseminated and implemented across the whole of Scotland as anticipatory care becomes part of the normal offer of the NHS.

5.6.2. The *Well North* programme builds on the momentum of *Keep Well* to deliver anticipatory care whilst adapting it to fit a rural setting. These remote and rural areas of Scotland pose specific challenges to the delivery of anticipatory care. *Well North* currently incorporates six projects across NHS Orkney, Shetland, Grampian, Highland and Western Isles that provide interventions to those at risk of preventable serious ill health. This programme is supported by £750,000 from the Scottish Government.

5.6.3. The ASSIGN Risk Calculator enables anticipatory interventions to be targeted effectively at those most at risk of developing serious illness. It is a risk score that calculates an individual's likelihood of developing CVD over ten years, and therefore suitability to receive advice and intervention. Studies have demonstrated that social deprivation is implicated in the development of CVD. ASSIGN factors in social deprivation and family history to improve its accuracy in Scottish circumstances. It is now available to GPs through the internet and has been embedded in a number of Glasgow GP IT systems. SIGN 97 recommends its use as the preferred risk calculation tool in Scotland.

5.7. Diabetes Awareness Campaigns

5.7.1. Government healthy living campaigns such as *Take Life On* and *Eat Well* target the general population with supportive messages and information designed to encourage maintenance or achievement of good dietary and physical activity habits. Currently, there is no evidence to show what impact these campaigns have on population groups at risk of Type 2 diabetes. Campaigns targeting at risk groups are therefore an important part of tackling prevention and complication issues. There is currently no Scottish programme to identify and treat impaired glucose tolerance (IGT) or impaired fasting glucose; i.e. those at highest risk of Type 2 diabetes. In addition to the risk of diabetes, IGT almost doubles the risk of heart disease.

5.7.2. Over the last three years, Diabetes UK has run two UK-wide campaigns, *Measure Up* and *Silent Assassin*, which have focused on raising awareness of diabetes risk. Evaluation of the *Measure Up* campaign, which targeted people at risk of diabetes by raising awareness of waist measurement as a key risk factor, showed that the campaign generated greater awareness in target groups with 10,000 people being tested for diabetes in Scotland. In 2009, Diabetes UK will be rolling out awareness roadshows across Scotland, which will include opportunities for individual risk measurement.

5.8. SCREENING

5.8.1. In July 2006 the National Screening Committee recommended that screening of the general population for diabetes should not be offered as it fails to meet a number of the Committee's key criteria. It does however recommend the introduction of a Vascular Risk Management Programme for individuals at high risk of developing cardiovascular disease and diabetes.

5.8.2. The most recent work on screening for diabetes undertaken in Scotland includes the Health Technology Assessment led by Professor Norman Waugh of Aberdeen University in 2007. The HTA found that although evidence of the benefits of a diabetes screening programme was growing, the viability of such a programme is still essentially uncertain. This was due in part to the lack of certainty of the optimal screening tool, and the lack of a randomised control trial that could demonstrate that screening would be effective in reducing mortality or morbidity.

5.8.3. The Scottish Public Health Network (SPHN) is currently conducting a Type 2 Diabetes Needs Assessment with an emphasis on screening and prevention. It is expected that by the time the revised Diabetes Action Plan is published, SPHN will have made recommendations on the way forward for screening and prevention.

ISSUES TO CONSIDER

- How do we encourage the prevention of diabetes?
- How do we target at-risk groups?
- What more could be done to tackle diabetes in deprived areas?

6. DEVELOPING A NEW DIABETES ACTION PLAN FOR SCOTLAND

You can get involved in this consultation in a number of ways:

By completing and returning the enclosed feedback form. This is also available on-line at www.scotland.gov.uk/diabetes where you may either complete it on-line or download it and return a completed form by post.

By e-mailing us at: betterdiabetescare@scotland.gsi.gov.uk

This document can be viewed at Scottish Health on the Web at: www.show.scot.nhs.uk. You can telephone Freephone 0800 77 1234 to find the location of your nearest public internet access point.

If you ask for your response not to be published, we will regard it as confidential and we will treat it accordingly. You should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

What Happens Next

We will consider all responses and views received by the closing date of 22 August 2009 and publish the revised action plan later in November 2009.

If you have any comments about how this consultation exercise has been conducted, please send them to:

Tom Pilcher
Long Term Conditions Unit
Scottish Government
St Andrew's House
Regent Road
Edinburgh
EH1 3DG

GLOSSARY

ASSIGN	Calculation tool used to estimate a person's risk of developing Cardiovascular Disease.
Anticipatory Care	Health programmes which check for the presence of disease. In Scotland this is delivered through the Keep Well programme.
Better Health, Better Care	The Scottish Government Action Plan for Health Care
BMI	Body Mass Index. A tool used to estimate a healthy body weight based on how tall a person is.
CHD	Coronary Heart Disease. A disease of the heart and coronary arteries caused by the build up of fatty materials in the blood vessels that supply the heart with oxygen.
CHP	Community Health Partnership.
Congenital	Condition that is present at birth as a result of heredity or environmental influences.
COPD	Chronic Obstructive Pulmonary Disease.
CSII	Continuous Subcutaneous Insulin Infusion or pump therapy.
CVD	Cardiovascular Disease.
DAFNE	Dose Adjustment for Normal Eating. A form of Structured Education for people with Type 1 Diabetes
DCFG	Diabetes Care Focus Group.
DEAG	Diabetes Education Action Group.
DESMOND	Diabetes Education and Self Management for Ongoing and Newly Diagnosed. A form of structured Education for People with Type 2 Diabetes
DiabNet	An out-of-hours service that operates across NHS Tayside, Fife and Forth Valley for children and young people with diabetes.
DKA	Diabetic Ketoacidosis. A complication of diabetes caused by the build up of by-products of fat breakdown called ketones. This occurs when glucose is not available as a fuel source for the body so fat is used instead.
DMEG	Diabetes Minority Ethnic Group.
DRS	Diabetic Retinopathy Screening.
eGFR	Estimated Glomerular Filtration Rate.
Epidemiology	The branch of medicine that deals with the study of the causes, distribution and control of disease in population.
Fasting Glucose	A measurement of the blood glucose in the morning prior to the ingestion of any food for the prior 12 hours.
GP	General Practitioner.
HbA _{1c}	Glycosylated Haemoglobin. A test that sums up how well controlled diabetes has been proceeding in the last three to four months.

HEAT target	Health Improvement, Efficiency, Access, Treatment target.
Health Board	Regional umbrella organisation for all health services with strategic planning and leadership provided by the Board.
HTA	Health Technology Assessment.
IGT	Impaired Glucose Tolerance. A state of raised or abnormal blood glucose levels.
LTCAS	Long Term Conditions Alliance Scotland.
MCN	Managed Clinical Network. Linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner unconstrained by existing professional and Health Board boundaries to ensure equitable provision of high quality, clinically effective services.
NHS QIS	NHS Quality Improvement Scotland. Leads the use of knowledge to promote improvement in the quality of healthcare for the people of Scotland.
OGTT	Oral Glucose Tolerance Test: The administration of glucose to determine how quickly it is cleared from the blood. Used to test for diabetes, insulin resistance and reactive hypoglycaemia.
Paediatric Care	The branch of medicine that deals with medical care of infants, children and adolescents.
Primary Care	The activity of the healthcare provider who acts as a first point of consultation for all patients.
PODOSA	Prevention of Diabetes and Obesity in South Asians.
QOF	Quality and Outcomes Framework.
Renal Disease	A disease or disorder that affects the kidneys.
RNIB	Royal National Institute for the Blind.
SCI DC	Scottish Care Information – Diabetes Collaboration.
SDFWDG	Scottish Diabetes Foot Workforce Development Group.
SDG	Scottish Diabetes Group.
SDRN	Scottish Diabetes Research Network.
SESP	Scottish Enhanced Services Programme for Primary and Community Care.
SIGN	Scottish Intercollegiate Guidelines Network. To improve the quality of healthcare for patients in Scotland by reducing variation in practice and outcome through the development and dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence.

Secondary Care	A service provided by medical specialists who generally do not have first contact with patients.
SLWG	Type 1 Diabetes Short Life Working Group.
Type 1 diabetes	The loss of insulin producing cells in the pancreas leading to a deficiency of insulin.
Type 2 diabetes	Insulin resistance or reduced insulin sensitivity combined with relatively reduced insulin secretion which in some cases can become absolute.

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APPENDICES

Appendix I

Building Blocks of Diabetes Care (2006)

Prevention and Early Detection

Health Promotion	Public Education	High-Risk Groups
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Chronic Disease Management – Care, Monitoring and Treatment

Information, Education and Empowerment (A)		Heart Disease and Stroke (A)	Eye Care (A)	Initial and Continuing Care
Information (B)	Psychological Support (B)	Kidney Problems	Neuropathy (Nerve Problems)	Diabetic Emergencies and Elective Care

Specific Groups

Type I Diabetes (B)	Children and Young People (B)	Minority Ethnic Groups (B)
Pregnancy and Sexual Health		Vulnerable Groups

Planning and Managing Services

Strategy, Leadership and Teamworking (A)	Education and Training for Professionals (A)	IM&T and Diabetes Registers (A)	Research and Development (B)
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Implementation

Implementation and Monitoring (A)

Community Issues

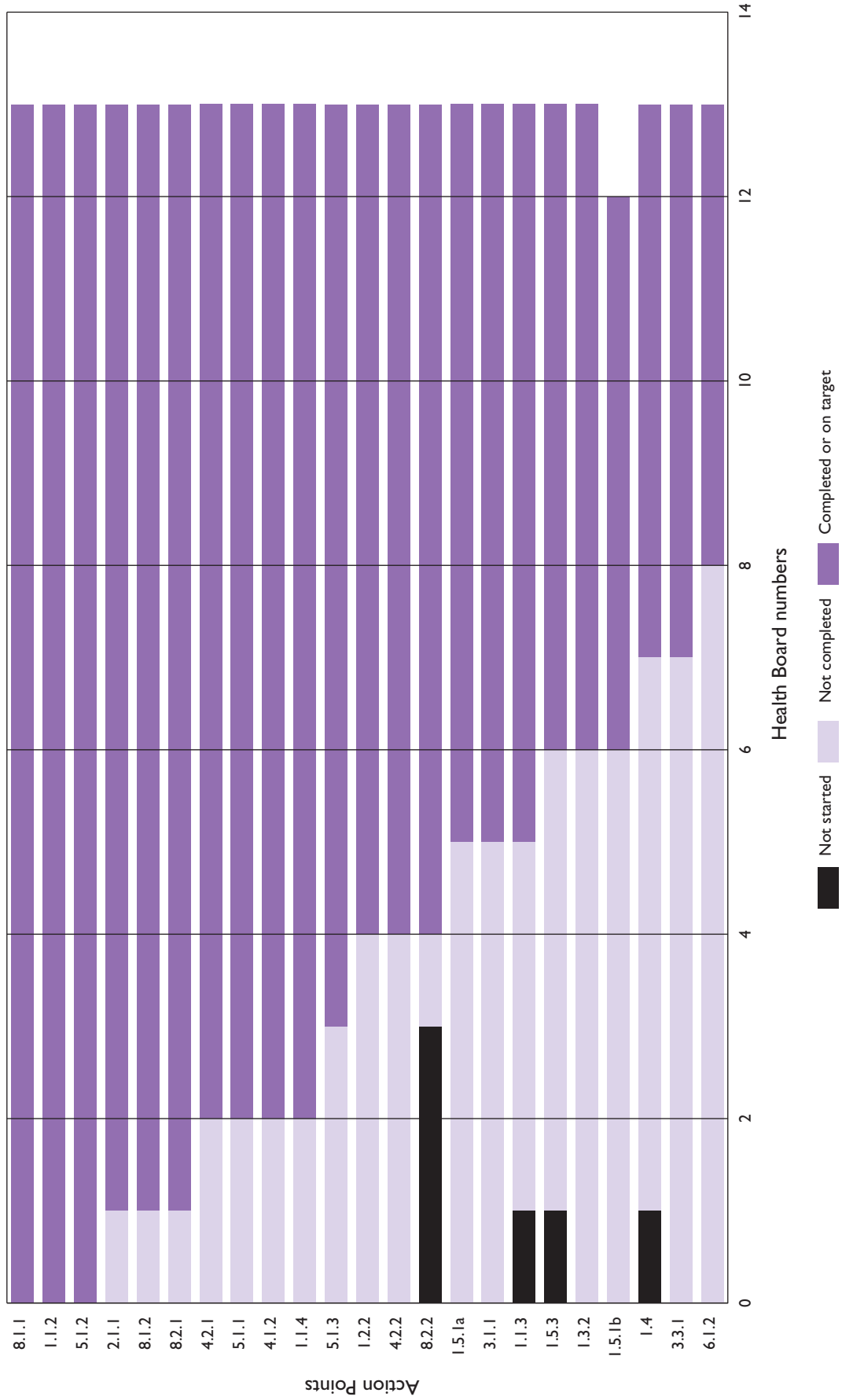
Community Issues – Issues involving other agencies
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2002

2006

Appendix II

Summary of progress against Action Plan for NHS Boards in Scotland as at September 2008



Action Point (Summary)

- 1.1.2** Work towards reducing incidence of diabetes emergencies in Type 1 diabetes.
- 1.1.3** Improve access to out-of-hours diabetes advice for families with children with diabetes.
- 1.1.4** Improve patients' experience of transitional care between children's and adult services.
- 1.2.2** Staff training courses informed by behaviour change models and the importance of patient empowerment.
- 1.3.2** Foot risk score recorded for at least 75% of people with diabetes.
- 1.4** Undertake needs analysis of their population to identify disadvantaged groups.
- 1.5.1 a)** Improve collection of data on ethnicity to over 50% of patients.
- 1.5.1 b)** Improve collection of data on ethnicity to over 80% of patients.
- 1.5.3** Undertake review of services for people with diabetes from minority ethnic communities.
- 2.1.1** Implement DRS programme.
- 3.1.1** Produce an 'insulin strategy'.
- 3.3.1** All newly-diagnosed patients with Type 2 diabetes to be offered structured education within 3 months of diagnosis. Perform annual survey.
- 4.1.2** Map current pattern of service delivery and produce a strategy to implement local pathways of care.
- 4.2.1** Monitor first outpatient appointments, routine outpatient waiting times and DNA rates.
- 4.2.2** Training and support mechanisms in place for lay members of MCNs.
- 5.1.1** Publish expected prevalence and identify gaps in service provision.
- 5.1.2** Over 95% of patients with data recorded for CHI, type of diabetes and date of diagnosis.
- 5.1.3** Over 80% patients to have a recent record of eGFR.
- 6.1.2** Produce a diabetes education strategy informed by a training needs analysis.
- 8.1.1** Improve quality and completeness of BMI and smoking status data to over 80% of patients.
- 8.1.2** Health improvement resources available to frontline staff.
- 8.2.1** Support measures to reduce the risk of people developing diabetes.
- 8.2.2** Apply lessons learned from preventive medicine initiatives, such as Prevention 2010.

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BETTER DIABETES CARE CONSULTATION FEEDBACK FORM

FEEDBACK FORM

Thank you for taking time to contribute to the Better Diabetes Care consultation. Please refer to the prompting questions at the end of each section within the consultation document. You do not need to answer all of the questions and all responses will be considered. Please use a separate sheet if necessary, clearly indicating the section to which your comment relates.

You can download or complete this form online at:

<http://www.scotland.gov.uk/diabetes>

Any queries you have can be sent to betterdiabetescare@scotland.gsi.gov.uk

SECTION 3: DEVELOPING HIGH QUALITY DIABETES CARE

Please give us your feedback below on the following sections:

- Supporting Improvement (see Section 3.3)
- Focussing Improvement (see Section 3.4)
- Psychological and emotional support (see Section 3.5)
- Diabetes related hospital admissions and inpatient care (see Section 3.6)
- Black and Ethnic Communities (see Section 3.7)
- Diabetic Foot Care (see Section 3.8)
- Retinopathy Screening (see Section 3.9)
- Structured Education (see Section 3.10)
- Professional Education (see Section 3.11)
- Research (see Section 3.12)
- Out of Hours Service (see Section 3.13)
- Pregnancy (see Section 3.14)
- Insulin Pump Therapy (see Section 3.15)
- Care Homes (see Section 3.16)
- Diabetes and kidney failure (see Section 3.17)

BETTER DIABETES CARE CONSULATION FEEDBACK FORM

SECTION 3: DEVELOPING HIGH QUALITY DIABETES CARE (continued)

Empty response area for feedback.

BETTER DIABETES CARE CONSULATION FEEDBACK FORM

SECTION 4: PUTTING PATIENTS AT THE CENTRE

Please give us your feedback below on the following sections:

- Support for Self Management (see Section 4.2)
- Supporting carers to support self management (see Section 4.3)
- Self Management and Vulnerable Groups (see Section 4.4)
- Involvement and participation (see Section 4.5)
- Peer Support (see Section 4.6)

BETTER DIABETES CARE CONSULATION FEEDBACK FORM

SECTION 4: PUTTING PATIENTS AT THE CENTRE (continued)

Empty response area for Section 4.

BETTER DIABETES CARE CONSULATION FEEDBACK FORM

SECTION 5: BETTER PREVENTION OF TYPE 2 DIABETES, EARLIER DETECTION OF THE DISEASE AND PREVENTING COMPLICATIONS

Please give us your feedback below on the following section:

- Prevention, Detection and Screening (see Section 5. Page 33)

Empty response area for feedback.

BETTER DIABETES CARE CONSULTATION FEEDBACK FORM

GENERAL COMMENTS

