

We welcome the opportunity to comment on this consultation paper. Our group includes diabetic patients as well as other medical expertise – and for this exercise we have had the benefit of comments from a retired diabetic specialist also.

In the introduction at para 1.4, it is mentioned that the increase in the incidence of diabetes can be attributed to better monitoring and data collection. Two other significant factors are an ageing population and the incidence of obesity.

In general, it is very clear that nearly all the problems could be improved by expenditure on staff particularly well trained diabetes nurse specialists who are worth their weight in gold as are dieticians, podiatrists, psychiatrists and psychologists.

Consultation Questions

SECTION 3: DEVELOPING HIGH QUALITY DIABETES CARE

Please give us your feedback below on the following sections of the consultation document:

- Supporting Improvement (see Section 3.3)
- Focusing 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 Disease

Drivers of Quality – (See Section 3.1.4)

As a group we are very concerned about asking GPs to aim for lower HbA1 levels in all those with diabetes. Of course good control is important particularly in pregnancy and in young people but to apply the same criteria across the board is not only foolish and unreasonable it is also extremely dangerous. For example someone in their 80s who lives alone could well die or be severely brain damaged from hypoglycaemia. Age, general health, psychological and social factors and many others should be taken into account in deciding the target HbA1 for any individual.

Supporting Improvement (see Section 3.3)

From a patient viewpoint we would welcome direct access to diabetes related health data and see it as a sensible aspiration. However, we would urge professionals not to lose sight of this – often something like this which would deliver patient responsibility can be left out in favour of professionals’ “needs”.

The updated SIGN guidelines may be further strengthened by focusing on structured ongoing education for both Type 1 and Type2 – and this requires trained personnel. (see note following)

In terms of delivering the effectiveness of the diabetes MCN, it may be worth considering the rationalization of the various sub-groups so that there is a clear unambiguous line of reporting to the CHPs and hence to the Health Boards.

Focusing Improvement (see Section 3.4)

We can improve paediatric care by having more diabetes nurse specialists. The same applies to most of the headings - nurses do go into schools but do not have enough time to do as much as they would like. The same applies for adults: nurses do go into prisons and old folk's homes. There simply are not enough of them to do all they would like to do and could do.

Psychological and emotional support (see Section 3.5)

Specialist nurses could also improve well-being if they had more time. We need more psychologists ideally guided by a liaison psychiatrist and diabetes specialist. The waiting time to see a child psychologist in Fife has been quoted to be over 6 months. Psychologists are not trained in diabetes so they need to learn about the disease and ideally be specifically connected to a diabetes team. There are many ways of measuring psychological well being.

Lothian runs a “buddy” service to help newly diagnosed patients. It may be helpful to extend this to offer a first line “ear” to those who need some support – although this also has training implications.

We suggest that psychological care in the form of talking therapies, especially for those suffering from depression who are already overweight, would be more appropriate (except obviously for the most extreme cases) than drug therapy, since many medications used in psychiatry, particularly SSRIs, have many unfortunate side effects that may include weight gain, and are also teratogenic. Therefore there needs to be greater provision of psychotherapy and counselling, which in the long term should be cost-effective if it leads to the resolution of emotional issues and the adoption of life-style changes.

It is particularly sad to note (para 3.5.1) that 50% of young people with Type 1 Diabetes suffer from depression. This must be addressed: more psychological therapy should be offered.

Exercise also has been prescribed for those suffering from depression, and this too should be considered. The Psychology Sub-Group (para 2.4) should be encouraged to look at all available therapies, not just CBT.

Para 3.5.3 ‘Staff education programmes’ should include staff support, self-care, and where necessary counselling to address those issues that affect staff as well as patients. It is not helpful for someone struggling with issues of weight gain, diet, etc. to encounter staff members who are obviously having similar difficulties: staff should lead by example, and where they find this difficult they should be given help. ‘Training NHS staff to improve their skills in behaviour change and psychological support’ needs to apply to the staff themselves.

Diabetes related hospital admissions and inpatient care (see Section 3.6)

Care in hospital which is often very poor would be enormously improved if a specialist nurse could go into every ward with patients with diabetes every day. They could see what is happening, teach ward

nurses, improve treatment and diets. More education, particularly about the prevention of ketoacidosis has reduced hospital admissions and could do more.

Black and Ethnic Communities (see Section 3.7)

In relation to ethnic minorities we noted there is much more experience in parts of England. In Bradford for example where over half the population is Asian a lot of money has been spent on trying to improve the situation and it would be worth finding out about their experience.

Diabetic Foot Care (see Section 3.8)

Again more staff. We were surprised that smoking was not mentioned here although that problem is addressed under cardiovascular disease. It is terribly rare for someone with diabetes who does not smoke to have an amputation but frighteningly common when they do. Reduction in ulcers and amputations are obvious ways of assessing foot care.

It would be helpful if Type 2 diabetics knew exactly what to look for so that they can self-examine their own feet and also if they knew what the warning signs were when more help is needed and exactly where to go for help and advice. We agree wholeheartedly with the objective of the Foot Action Group to have consistent patient information available nationally.

One of our members mentioned that when he was originally diagnosed and told about the importance of foot care he said he already attended a chiropodist. It appeared that because of this all interest in this aspect by the doctor was lost. He was not informed that podiatry may be available or what was available if he could not continue to pursue it privately. This is just one instance of the confusion that surrounds the provision of podiatry. It would be helpful if the system was clear and simple.

Retinopathy Screening (see Section 3.9)

Screening and treatment has improved enormously over the years. In Fife it has been shown that in Type 1 diabetes no one went blind if they had regular screening. Vans and road shows are great for publicity and do pick up some people who might not otherwise be screened but it needs to be a regular permanent system. I should like to see GPs have targets for that, if they do not have already, as they are the people with records of all those with diabetes.

Structured Education (see Section 3.10)

We see structured education as key to good self-management of diabetes. Even before diabetes develops, it would be helpful if health educators in schools (nurses or teachers) explained to children the importance of eating a good diet, staying within sensible weight parameters and if possible avoiding smoking and drinking to excess. This message needs to be delivered throughout school, and pre-pregnancy – throughout life really.

Once diabetes has been diagnosed then it is imperative that for Type 1s especially that there is good education and support, and for Type 2s there is good initial information and education. Those caring for people with diabetes have always striven to give good education about how to care for themselves and we recognize again that the limit is staff. There are many excellent programmes – for instance one of our group was involved with a system where in addition to special education for Type 1 diabetes there was excellent group hospital-based education for all newly diagnosed Type 2 diabetes but it had to be stopped because of lack of staff. Educating health workers themselves needs money and staff.

We would also suggest that there is an ongoing need for further education when for example a patient starts to take insulin (having previously been on tablets), or when research changes the way medication is delivered (pumps) etc. If these programmes become available then GPs might be encouraged to use them if a QOF point were at stake?

Professional Education (see Section 3.11)

All of the initiatives surrounding diabetic care require health professionals to be up to date with current practice and as ever resource is required to deliver it.

Research (see Section 3.12)

We could increase public involvement in research if there was less red tape. Many of the important studies which were done in the past are no longer done because of the masses of forms and time taken to get through ethical committees and then the time taken for informed consent etc etc have now got to the point that many people just give up trying. If there was some way to encourage informed consent in trials, with a pre-screened population, this would help.

Out of Hours Service (see Section 3.13)

Perhaps more training (or better algorithms) in diabetes for NHS 24 staff and possibly paramedics would help.

Pregnancy (see Section 3.14)

The outcome is now generally good for type 1 diabetes as there are centres of excellence running contraceptive services and pre-pregnancy clinics. The problem now is Type 2 diabetes which has become so much commoner in the child bearing years. Most of these patients are not seen in hospitals and contraceptive advice and pre pregnancy care is often not given. This needs more awareness and again more staff.

Insulin Pump Therapy (see Section 3.15)

Type 1 diabetics are often of the opinion that pumps go to those who fail to regulate their insulin therapy properly and that those who do maintain reasonable control without a pump will not be offered one. There has to be a recognition that quality of life is important too and that pumps should be a matter of choice and appropriateness rather than a “reward for failure”. We would also discourage any pre-judging of a patient’s ability to use a pump.

Care Homes (see Section 3.16)

Staff in care homes need time to train in diabetes care and there needs to be provision to release them for such training.

Diabetes and Kidney Disease

Experience of diabetic patients is that the eGFR test is not well explained – nor is it well understood. There seems to be a dearth of information available and it would be helpful if this gap could be plugged both in terms of information and of education.

SECTION 4: PUTTING PATIENTS AT THE CENTRE

Please give us your feedback below on the following sections of the consultation document:

- 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)

We welcome the emphasis now being put on the patients and carers and their needs. Most people prefer to have a say in how their health is managed and take a much more active part in it when the benefits can be demonstrated.

In terms of ensuring people with diabetes and their carers are able to participate in local service planning there needs to be a functioning PPF, membership of local MCNs, and possibly patient groups established at GP surgeries.

The Lothian “buddy” service would help newly diagnosed patients and there needs to be a concerted effort to recruit and train volunteers in the aspects of being a buddy.

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)

We recognize that the plans for reducing obesity, promoting healthy eating and stopping smoking specifically targeting more vulnerable groups is exactly what needs to be done as far as prevention is concerned. The problem is so far it has not worked well. Our group felt quite strongly that the problem is cultural not financial. Going to the very young is clearly important but to succeed in changing culture on a large scale seems to be incredibly difficult.

A specific suggestion would be for an annual check to be offered to all those over 40 (including ethnic minorities of course) with obvious risk factors – e.g. obesity or family history.

In conclusion our diabetic expert tells us that those working in the field have known for years what to do. The problem is staff to do it and adequate financial support for them.

South Edinburgh Health Forum
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