CONSULTATION QUESTIONS

1. The strategy outlines a care pathway (page 10).

(a) If you are a service user and/or carer, please tell us what difference you believe the implementation of the pathway will make to the services you experience.

Diabetes UK Scotland is the charity for people with diabetes. One of the largest patient bodies in the country, we have over 10,000 individual members and 36 voluntary groups in Scotland. Diabetes UK Scotland campaigns on behalf of people with diabetes, provides information and support and funds research.

Diabetes is a condition where the body can not use glucose (sugar) properly. If untreated diabetes can lead to heart disease, stroke, kidney disease, blindness and amputations. There are two forms of diabetes – Type 1, which usually develops in younger people, and Type 2, which largely affects people over the age of 40 and is the most prevalent form of the condition. There are over 250,000 people with diabetes in Scotland. Between 2006 and 2011 the number of people diagnosed with diabetes has grown from 196,801 to 247,278, an increase of 25.6 percent. It is estimated that there are 49,000 people who have diabetes and do not know it and a further 620,000 are at high risk of developing Type 2 diabetes.

The mortality rate for patients with Type 1 diabetes is 2.6 times higher than the general population, for patients with Type 2 diabetes the risk is 1.6 times higher. The rapidly growing scale of the condition is alarming, as are the associated care and treatment costs. NHS spending on diabetes was over £1 billion in 2011, 10 percent of the NHS budget. 80 percent of NHS spending on diabetes goes into managing avoidable complications.

Retinopathy (damage to the retina or 'seeing' part of the eye) is a complication that can affect anyone with diabetes. It may have an impact on the eyes in several ways, the most important being the effect that it has on the retina and the blood vessels within the retina. This is known as diabetic retinopathy. Retinopathy is the most common cause of blindness among people of working age in the UK. The World Health Organisation (WHO) has classed diabetic retinopathy as a priority eye disease.

Whilst rates of retinal screening are generally improving and almost 90 per cent of people have a check every 15 months, 51.2 per cent for those with Type 1 and 25.2 per cent for those with Type 2 diabetes have damage to their eyes as a result of having diabetes over a long time without optimal control or where Type 2 diabetes had not been detected earlier. 19.3 per cent of people initially diagnosed with Type 2 diabetes already had signs of retinopathy.

(b) How can we best ensure that services and support meet your needs?

(c) If you are a care provider, what changes will you need to make to implement the pathway?

(d) How will you make these changes?

2. The strategy identifies key factors that need to be in place to ensure the pathway is successful (Page 11 para 6.7).

(a) Which of the key factors are most important for a successful pathway?

All of the factors mentioned are important for the success of the pathway, for a strategy there is nothing that can be disagreed within these points. There needs to be a consistent approach to all the strands highlighted to insure that they can work in conjunction and independently.

(b) Which are the most challenging to put in place?

The commitment for integrated service provision and basic screening are laudable however there needs to be a recognition that for these services to succeed the targets must be aware of their existence. A strong element to the success will also be ensuring that there is sufficient capacity throughout Scotland. As has been seen in diabetes care there are marked differences in delivery of services between health boards. This leads to the inconsistency of provision that can see the people in most need missing out on vital services. Where you live has an impact on how well the outcome of your diabetes care will be. In terms of key outcomes, there is great variability across all the key health indicators required to manage diabetes well.

The challenge for the strategy will be to ensure that patients do not miss out on essential health checks.

(c) Do you think that any key factors have been missed?

3. The strategy identifies areas for action that should be addressed going forward (Page 13-16)

(a) Which of the areas for action will be the most challenging to implement?

It is important for the strategic framework to give aims and purpose and any following policy must adhere to this. The strategy must provide direction and goals and can not focus on details that should be contained within the ensuing policy. However there must an understanding of the wider context, the fact that sensory impairment can be a result or associated with other conditions.

Diabetes UK Scotland agrees with the intent, emerging themes and majority of the recommendations within the consultation, however there are certain areas that we would like to see clarification and focus on specific issues. These are laid out below:

As has been shown diabetic retinopathy is part of the wider potential consequences of diabetes. Any strategy must work with existing services and incorporate aims and goals of other conditions that are associated with sensory loss. Within these considerations there must be an acknowledgment that costs and funding can not be taken from other services to finance any resulting policy from the strategic framework. In recommendation 4 (p.15) the document states that *"Scottish Government will provide funding to local partnerships for 2013/14 and 2014/15 to assist with work that will be required to implement this group of recommendations"*. Have there been forecasts on cost created and projections to ensure continued funding or the ability to achieve self sustaining funding?

Recommendation 5 states that *"There should be robust systems for maintaining information locally, and sharing this between agencies, in relation to people who have received a diagnosis of a sensory impairment at any time from birth onwards."*

If you are from a Pakistani community you are 9 times more likely to develop Type 2 diabetes. 70% of children/young people with T1 live in areas of deprivation. Diabetes affects people from black, asian and minority ethnic communities disproportionally than the white community this is also the case for those living in deprivation with the link between Type 2 diabetes and diet being a strong factor in areas of deprivation where opportunities for healthy food are constrained. Families living with children who have Type 1 diabetes can often find themselves struggling as one parent will be have to provide care needed to manage the condition in children and adolescents, affecting the economic situation.

Compounding this is the fact that these communities are hard to reach, the systems that are created must record and target these communities to ensure equitability.

(b) Which of the areas for action will make the biggest difference and why?

(c) Are there any other areas for action that you would like to see included within the strategy?

4. Please comment on the current provision of sensory impairment services as either a service provider or service user. If you have any experience of sensory impairment services, please let us know what you think of them: this should include any experience of one-stop shops.

Please see question 1.

5. What difference will the implementation of the strategy make to your life?

6. Does this strategy properly reflect the current climate and developments in policy and practice for children and young people particularly in relation to the Getting it Right for Every Child approach and the Doran Review?

Getting it Right for Every Child is important for everyone who works with children and young people. As has been identified in the pathway a “robust arrangement for helping people through periods of transition and in moving from children’s to adult services”.

The experience in people managing their diabetes can struggle in the transition from children’s to adult services and has been a repeated concern of Diabetes UK Scotland. As was mentioned in the beginning of the consultation, bringing a human rights based approach has been key to Getting it Right for Every Child, the inclusion within this strategy must be at the heart of the document.

7. Do you have anything you wish to add to the Sensory Impairment Strategy or any other general comments that have not been covered by the questions?