Diabetes Scotland

Diabetes Scotland welcomes the Health and Sport Committee inquiry into “Integration Authorities Consultation with Stakeholders”.

Scotland has the fifth highest incidence of Type 1 diabetes in the world and has an increasing prevalence of people with Type 2 diabetes.

With over 285,000 people with diabetes in Scotland and around 1 million at increased risk of developing Type 2 diabetes; one in five people have diabetes or at risk of developing the condition. There are more people living with diabetes than with coronary heart disease. Two and a half times more people have diabetes than all cancers combined. At any time between 15 – 20% of patients in Scottish hospitals have diabetes.

Diabetes has a massive impact on the wellbeing of people living with diabetes and their families. It affects people’s physical, mental and emotional health. For example depression is at least twice as common in people with diabetes as in the general population, but this common comorbidity is frequently underdiagnosed and undertreated.

It is not surprising, therefore, that diabetes costs NHS Scotland around £1 billion each year, of which 80% (£800 million) is spent treating potentially avoidable complications. Furthermore, 12% of the total inpatient budget in Scotland goes on treating diabetes and its complications.

Integration authorities clearly need to understand the impact of diabetes on their local population and the potential savings to be made through prevention of Type 2 diabetes and appropriate treatment and support for people living with Type 1 and Type 2 diabetes to reduce the risk of serious complications and improve quality of life.

To help in forming a response, Diabetes Scotland asked its network of local groups, which operate in communities across Scotland, of their experiences of integration to date. Below we have collated the responses of the 20 groups that participated.

Do you know how and when you can get involved with the Integration Authorities to influence decision making?

A typical response from our groups is given below:

“There were news bulletins at the inception of the IJB but no one really understands their work or the relationships and lines of authority between various bodies on the IJB and the expected outcomes of the IJB.” Diabetes Local Group

Seven respondents said that they or someone in their group had received information from the Integration Authority with regard to health and social care integration. Two of these were because of representations from Diabetes Scotland. None of the groups or individuals knew how to contact their local Integration Authority.

“I am surprised at how little I know about this partnership. I have never seen it advertised and would have no idea at how I could have become involved. With three members of my family with Type 1 and myself having Type 2 we like to keep in touch
with changes. I was involved with the first SIGN guideline for children/young people and fully participated by reading all the research papers and scoring them and it was pointed out to me at that time how important input from people living with diabetes was to them.... I feel it is extremely important that more members of the public should be actively involved especially at this time when everyone is looking at cutting budgets.”

Were you consulted in the preparation of the strategic plans or involved with the work of the Strategic Planning Group?

Only three of the local groups which provided responses have had some involvement with their locality plans. Given the significance of the prevalence rate of diabetes, this is a large oversight from the strategic planning groups.

Have you been involved with the work of the Integration Authority following the publication of the strategic plan?

Only two groups responded that they have been involved in work with the Integration Authority following the publication of the strategic plan. They were engaged with the Carer and Service Users Group.

It is not clear who to contact with the Integration Authorities. Diabetes Scotland submitted Freedom of Information requests to Integration Authorities and Health Boards as there was confusion regarding responsibility for diabetes services carried out by primary care. The responses we received were disappointing: Integration Authorities passed responsibility to local Health Boards and the same in reverse. This is highly concerning regarding accountability for some key areas of diabetes treatment.

Have you been involved with the work of the localities/what involvement would you like to have?

One response said they would like the Managed Clinical Network patient representative to be able to report back what is happening with the Integration Authority.

The localities should have a clear workplan for the year, published well in advance and each workstream should publish arrangements for consultation on reshaping of services and on budgetary changes.

Due to the complex nature of diabetes, this will not mean that people are only consulted on “diabetes” services, but on the complex range of services that people living with diabetes receive – podiatry, ophthalmology, mental health services, etc.

The care of people living with non-complex Type 2 diabetes is coordinated by primary care and so large numbers of patients have an interest in how that care is delivered through GP practices, with current intelligence suggesting wide variation in care.

Type 1 diabetes has a serious impact on young people, on their schooling, and their ability to live a full life outside of school. The impact on parent carers can be enormous. Families need to be consulted about changes to young people’s services.

A disproportionate number of people with diabetes are of South Asian origin who may develop the condition at a younger age. Their specific voice needs to be heard in service design.
Do you think that your involvement with the Integration Authorities has had an impact on decision making?

There was only one response Diabetes Scotland believed that their participation had an impact on decision making due to their involvement in a local working group that fed into the Integration Authority. No other respondents believed that they had any impact on decision making.

What could be done to improve the communication from the Integration Authorities? What could be done to ensure greater collaboration and engagement in the decision making process of Integration Authorities?

As the leading charity for diabetes across Scotland there has been no formal consultation with the organisation regarding to strategic planning from any of the 32 Integration Authorities. To a large extent this has been replicated over our local groups with a small number being on patient focus groups. Integration Authorities must be more transparent, accountable and easier to contact.

The majority of responses were focused on greater Integration Authorities interaction. In addition there needs to be a clearer understanding of the aims, objectives and who to contact. Examples included:

“Integration Authorities need to inform the public who the members are and how they can be contacted.”

“If the Integration Authority came up to meet people it would be a good place to start.”

“Integration Authorities should clearly state or more particularly restate their aims and objectives together with the costed business plans to the (diabetes) group so that members can make informed contributions to help the Integration Authorities discussion and decision making.”

“The relationship between Local Authorities, Health Boards and other agencies should be explicitly detailed so that the overall picture can be understood by our group, empowering us to make the best contributions possible to the work of the Integration Authority as and when required.”

“Dialogue and constructive, collaborative relationships with local groups should ensure that an informed and tailored diabetes service is delivered locally.”

Diabetes Scotland suggests to the Committee that involvement of people living with diabetes and their caregivers/families, in Integration Authorities planning and consultation has been woefully inadequate. The diabetes community is one of the biggest constituencies in Scotland. Failure to address their needs will not only lead to poorer health outcomes, but will also miss the opportunity to reduce unnecessary spending on diabetes complications.