

Parkinson's UK in Scotland

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

Parkinson's UK in Scotland has a Scotland-wide focus and we are best understood as a patient representative group as we are not a direct provider of social care support. We have staff, volunteers and supporters are based in communities across Scotland, and have had some experience of engaging with Integration Authorities on specific matters relating to local Parkinson's services, but – in common with many Scotland-wide charities - we lack the capacity to engage strategically and systematically with Integration Authorities across Scotland. Parkinson's UK in Scotland does not automatically link in with Third Sector Interfaces in relation to their representative role with Integration Authorities, although we do have "on the ground" links with many local TSIs, which largely relate to volunteering and community links. Our experience is that TSIs are also very varied in terms of the ways in which they operate and the information available about their engagement with IAs.

We have found information about Integration Authorities is extremely difficult to come by, with no consistency about the information available online about IAs, their membership, their decisions and plans. There is so much variation in how IAs are working, that it is very difficult to support people about how to engage with their local IA, and we have to adapt our approach in every case. Our overall impression is that there is a major lack of transparency about Integration Authorities and their decision making, and that is generally very difficult for organisations and individuals to know how to engage with them.

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

Parkinson's UK in Scotland has been consulted in the preparation of some strategic plans, but this has been dependent on our locally based staff / volunteers being included in local networks. It is by no means systematic, and we currently lack staff capacity to respond in detail to strategic planning work across the whole of Scotland. We have a strong network of volunteers and people affected by Parkinson's across Scotland, but we are very aware that people affected by Parkinson's are living with a very complicated condition, with a considerable impact on their day-to-day lives. Engaging with strategic planning can be complex, and it is challenging for us to provide volunteers with the support they would need to participate fully in these processes.

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

No.

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

Again, this has been very variable, and dependent on the extent to which local staff and volunteers are bedded into local networks.

Given that there are typically hundreds of people affected by Parkinson's in each mainland locality, and that people with Parkinson's typically have increasing service requirements as their condition progresses, we would like to see people with Parkinson's being involved in the planning of local services. We would like to see some resource put into supporting local people to engage with these processes, and wonder if there is a role for the Scottish Government / Healthcare Improvement Scotland and others [Our Voice](#) project, or TSIs, in providing this support locally.

Do you think that your involvement with the IAs has had an impact on decision making?

Parkinson's UK in Scotland is very conscious that it is very early days in our relationships with IAs. We have had a positive result with one IA with whom we have engaged on matters relating to specific services, and have had no response from another. We are not aware that we have had any impact on strategic decision making outwith this local engagement.

What could be done to improve the communication from the IAs?

We believe that almost anything would be an improvement on what is currently available. As a minimum, each IA must have a visible web presence, with clear membership and contact details for members provided, along with minutes of meetings, papers, locality and strategic plans as well as its recent decisions and actions. It would be helpful for the IA to engage directly with local community groups and let people know how to engage. Regular newsletters in an accessible format for stakeholders, including organisations like ours, would be helpful.

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

Parkinson's UK in Scotland would welcome greater collaboration and engagement with IA decision making. However, this will require greater openness from IAs themselves, and more support for local people and groups wishing to become involved. The role of TSIs needs to be clarified, with clear information from them to stakeholders locally. Additional resource may be required to enable TSIs to perform a properly representative function. This could include resourcing or supporting the TSI to engage with local people with an interest and reflect their views to the IA.

We would also welcome some opportunity for national organisations like Parkinson's UK in Scotland to feed in our strategic priorities to IAs at a Scotland-wide level, recognising that we have very limited capacity to do this separately for each IA.

About Parkinson's

More than 11,000 people in Scotland have Parkinson's. About one in ten of these people are classified by ISD as at high risk of hospital admission in the next year.

Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely. Their muscles can become stiff and sometimes they freeze suddenly when moving. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact on peoples' day-to-day lives. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'.