Introduction
There are more than 12,000 people with Parkinson’s in Scotland, and Parkinson’s UK is here to make sure that nobody has to face Parkinson’s alone. We work with people with the condition, unpaid carers, families and friends across Scotland. We have more than 40 local groups, and a team of community-based local advisers who offer free and confidential information and support.

We also work with local people affected by Parkinson’s to improve NHS and other services, through the health and care professional-led UK Parkinson’s Excellence Network, which has three regional groups in Scotland, and with NHS boards and integration authorities.

We have recently established an online network of around thirty people with lived experience of Parkinson’s who are interested in improving services and support for people in their local area, or nationally. This response is informed by members’ responses to the Committee’s questions, as well as by the charity’s recent experiences of engaging with NHS bodies.

Do you trust NHS boards to make decisions that are in the best interests of the public?
People with Parkinson’s and carers often have a level of cynicism about the extent to which NHS boards make decisions in the best interests of the public.

In some high profile cases, such as NHS Greater Glasgow and Clyde’s attempt to close the Lightburn Hospital in the East End, local communities, including our East Glasgow Parkinson’s Support Group, local councillors and MSPs had no trust at all in the board. The board’s initial denial of a leaked paper outlining plans to close the hospital, combined with the previous history of attempts to close the facility and board underinvestment in the site meant that people simply did not trust the board to act in their best interests from the start. People with Parkinson’s locally believed that board officials had already made up their mind to go ahead with closure and that it was a waste of time to engage with them about the plans. A newspaper article published during the engagement period in which the board’s
then Director of Planning stated that the hospital was “past its time” confirmed the view locally that the board was not interested in hearing from people affected by its plans.

Another example, not directly related to Parkinson’s, is the suppression of chronic pain waiting times in NHS Dumfries and Galloway, resulting in an intervention from the Information Commissioner to release the data that had been withheld.

Not only do these cases have a negative impact on the people caught up in disputes, but media coverage of NHS boards getting it wrong also contributes heavily to public mistrust of NHS boards.

In our experience, people affected by Parkinson’s perceives that those who run NHS Boards have little contact – or insight into – the issues that people like them are facing. This comment is fairly typical:

“[The] Health board and local authority social work must be approached and made aware of how the lack of interest and finance is very worrying for future for patients and families”

Participant in focus group on NHS services in Ayrshire, May 2017

It is also difficult for people outside the staff structures of the NHS to see how decisions are made, and how they can influence what happens, and this lack of connectedness also contributes to a lack of trust.

But there are also concerns when NHS boards follow policies that appear not to consider the needs of people with Parkinson’s, or could even threaten successful services upon which people depend. One example is that a push towards making more outpatient appointments available locally could have unintended consequences for people who benefit from other models of care. Day hospital clinics are very effective for people with complex conditions like Parkinson’s because people typically benefit from seeing several members of their multi-disciplinary team on the same day, professionals work together to provide holistic care, and care is less fragmented. It is important to make sure that boards listen to what different groups of patients need, and do not pursue one-size fits all solutions for all.

Parkinson’s UK accepts that taking decisions about balancing the resource and care needs of different groups in the population is a major challenge, particularly in the context of rising demand and austerity. We also believe that most NHS employees - whether clinical, support staff or management - are there because they want to improve lives and health for the people they serve. People affected by Parkinson’s are typically well-informed and engaged and their lives involve a great deal of interaction with NHS services. When they tell us that they do not trust NHS boards to make decision in the best interests of the population, it is clear that there is a major problem.
**Are NHS board decisions open and transparent?**
Parkinson’s UK recognises that NHS board papers and minutes are made available, and this information can be very valuable when seeking to understand board decisions.

It is important to appreciate that these papers only tell part of the story, and in common with most large organisations, much of the work to push through decisions takes place before discussions reach the board meeting. One member of our Parkinson’s Voices group had a look at his local board’s published papers and commented:

“I have had a browse through some minutes and reports….. It seems … that the board meetings are more of a rubber-stamping forum and the minutes are quite uncontentious. I did have a look through a paper focusing on strategic change…. My main impression was that whilst all the aspirations and proposals were admirable they were typically ‘high level’ and abstract in nature. Thus it was not clear how the strategy would be implemented and this is I suspect the kind of detail that patients/public want.”

Parkinson’s Voice member, e-discussion, February 2018

In addition, it is much harder for members of the public without the support of organisations like Parkinson’s UK, other local or national charities or statutory bodies like the Scottish Health Council, to know that board papers are published and where to look for them.

**How accountable do you feel NHS boards are?**
“…accountability is paramount and members of the public, including support and pressure groups, need to be actively engaged in scrutinising the work and decisions of the health board.”

Parkinson’s Voice member, e-discussion, January 2018

It is very important to the people with whom we work that NHS boards are accountable for their decisions, and that the voices of people affected by proposed service changes are heard.

Parkinson’s UK has experienced major variations accountability and responsiveness between different NHS boards. We have previously outlined our significant concerns about the quality of the engagement and consultation carried out by NHS Greater Glasgow and Clyde about the proposed closure of Lightburn Hospital in 2016-17, identifying concerns about aspects of the consultation exercise and documents produced by the board to support its decision.

During the process, Parkinson’s UK felt it was necessary to brief MSPs and write to the board and the Scottish Health Council with a detailed breakdown of how each of the major service change criteria could be applied to the Lightburn proposals to ensure that the plans were deemed to be a major service change and therefore subject to Ministerial approval.
Parkinson’s UK found engaging with NHS Greater Glasgow and Clyde at this time very difficult. There appeared to be very limited understanding among senior officials that the role of an organisation like ours is to represent the views of people affected by Parkinson’s, and ensure that where they have concerns about the future provision of their vital care and support, that these concerns should be both heard and addressed. Rather, it appeared that there was an expectation that Parkinson’s UK staff would tell people affected by Parkinson’s what they should think – and that what they should think was in line with the board’s proposals. This top-down model of decision making may help to explain why individuals and communities did not feel heard during this process, and may also help to explain some of the trust issues that can exist between NHS boards and local communities.

We also previously noted that Parkinson’s UK was able to step in to conduct a consultation meeting with 33 people with Parkinson’s and unpaid carers to explore the issues around different hospital sites. While the board committed to site the Parkinson’s service in line with the preferences of the group, we were concerned that other groups of service users did not have an organisation like ours to act as an intermediary, and that their views were not captured or fed back to the board. It is clear that it is much more difficult for service users who do not have the support of another organisation to make their views heard when service changes are proposed. It is not clear how the board can be accountable to the population it serves when this is the case.

Our work in other parts of the country reveals that there could be other issues of accountability. Integration has complicated the picture, as in many cases we are dealing with integrated joint boards (IJBs), rather than health boards. There appears to be considerable variation in how this is affecting accountability across Scotland.

People affected by Parkinson’s in one NHS board area have told us that there is ambiguity about who is ultimately accountable for making decisions about Parkinson’s services, and that the buck is being passed between the board and the health and social care partnership with nobody taking responsibility for decision making. Our members believe that this is making it impossible to achieve improvements to local Parkinson’s services, and report real frustration.

In NHS Ayrshire and Arran, there are significant capacity issues within the Parkinson’s service. One consultant and two Parkinson’s nurses are supporting over 600 people with Parkinson’s across the Board area. There is a critical shortage of consultants in medicine for older people in Ayrshire, with nearly half (47.6%) of posts vacant.

The North Ayrshire Health and Social Care Partnership is coordinating the response for the whole board area. While HSCP officials have been engaging with Parkinson’s UK, local people affected by Parkinson’s and NHS staff about the Parkinson’s service, we believe that there are real limits about what can be achieved if the HSCP is unable to address the critical issue of staff resources. Engagement with people who use services must be backed with the ability to make the changes needed. These will not always relate to resource allocation, but where they do, we are concerned that engagement with people who use services will appear tokenistic if agencies are unable to act.
We had a different experience in Moray, when we worked on a local crisis in staffing the Parkinson’s service. We engaged with both NHS Grampian and the Moray Health and Social Care Partnership, and found both to be willing to work with us, and with local people affected by Parkinson’s. Officials acted quickly to resolve the problem, and continue to work with local people to develop the services needed to support people with Parkinson’s in the community.

**How effective are NHS boards at delivering health services and improving the health of their population?**

“If I was to be asked about the work of our health board and its current priorities, I would at best be making informed guesses rather than being able to quote any information shared. I would have difficulty describing any process about how decisions are made. Despite having lived with [my husband’s] Parkinsons for almost 23 years, I can recall no occasion when we have been asked for our views about the health provision locally.

Despite that, I would say that the health support [my husband] has received has been excellent.

So, I have no idea about any mechanisms which might exist for us as members of the public to influence the work of the health board locally. Overall, we are satisfied with the health support provided, but would, from time to time, have had views about support which could be improved”

*Parkinson’s Voice, e-discussion, January 2018.*

When we asked our Parkinson’s Voices this question, the responders were emphatic that they were happy with the NHS services and support that they received. We believe that this reflects the close relationships that many people with Parkinson’s and their families develop with the expert teams that support them. In our most recent *Parkinson’s UK Audit*, 87% of respondents to our Patient Reported Experience Measure in Scotland said that they always or mostly felt listened to by their Parkinson’s team, and 69% believed that they were always or mostly involved in decisions about their care. Our *Your Life Your Services Survey* duplicated these questions the figures for those using any Parkinson’s service in Scotland were 77% and 74% respectively.

Despite major issues and concerns with NHS board governance, it appears that overall people with Parkinson’s believe that the healthcare that they personally receive is appropriate. Of course, in cases where boards make decisions that compromise care quality, or fail to act to improve services, people are likely to have very different views.
**About Parkinson’s**

More than 12,000 people in Scotland have Parkinson’s.

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. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact. 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’. There is no cure.

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