1. Are services safe, effective, and evidence-based?
Parkinson’s UK believes that NHS services endeavour to be safe, effective and evidence-based. We recognise that the Scottish Patient Safety Programme has had an enormous impact in reducing unnecessary deaths.

However, we would like to highlight medication issues for people with Parkinson’s as an area where too often care is unsafe, ineffective and not evidence-based.

People with Parkinson’s are at very high risk of hospital admission. They are also typically prescribed complex and bespoke medication regimes. If people do not receive their Parkinson’s medications at the correct time and dose, they can become very unwell very quickly. They may:
- be unable to move, speak, eat or swallow
- experience uncontrolled movements
- have distressing psychotic symptoms

It can take weeks to restore effective symptom control, and some people never recover fully.

We estimate that more than a quarter of all people with Parkinson’s are admitted to hospital each year in Scotland, many of them on more than one occasion.

One NHS Board in Scotland now has audit data for all Parkinson’s medication issued in all of its wards against prescribed times. In 2015, on a typical hospital ward, fewer than half of all Parkinson’s medications were administered on time. This is in line with data from our UK Parkinson’s Audit, which also showed that fewer than half of those admitted to hospital always got their Parkinson’s medication at the right time.

We are working on a number of projects to improve medication practice through the UK Parkinson’s Excellence Network, including one in the North of Scotland to investigate which interventions are most effective in ensuring that people get their Parkinson’s medication on time.

2. Are patient and service users’ perspectives taken into account in the planning and delivery of services?
People with Parkinson’s have very mixed experiences on this issue.

What we are doing to support NHS Parkinson’s Services
Parkinson’s UK is supporting NHS Parkinson’s specialist services to work with people with Parkinson’s and unpaid carers within the UK Parkinson’s Excellence.
**Network**, which brings together health and care professionals who work with people with Parkinson’s to share skills, tools and insights and improve the quality of care. In addition to the wider network of professionals across the UK, there are three multi-disciplinary regional groups in Scotland, covering the West, East and North of the country. The groups are led by experienced Parkinson’s clinicians. People with Parkinson’s and unpaid carers are also involved in the groups.

Our 2015 UK Parkinson’s Audit included a Patient Reported Experience Measure (PREM) for the first time, to enable services to capture the views and experiences of people with Parkinson’s and carers. Across the UK, 5,384 people participated, enabling recommendations to be made to improve Parkinson’s support – two of the five priorities for change that were identified were based on information from the PREM.

We are now supporting services to provide better information after over a third of participants said that they did not receive enough information at diagnosis and when medication was changed. In NHS Grampian, Parkinson’s clinicians are now working with people with Parkinson’s and carers to develop and test a standardised information pack to be given to people at diagnosis, which can be implemented across the rest of Scotland and the UK.

Improvements in inpatient medication management have also been prioritised for action as a result of the PREM findings, which were that fewer than half of people who were admitted to hospital got their Parkinson’s medication at the right time.

**Wider issues within NHS Scotland**
The UK Parkinson’s Excellence Network is playing a vital role in capturing and reflecting the experiences of people with Parkinson’s and unpaid carers. Unfortunately, these are not routinely captured or addressed by the NHS, including in NHS Scotland. People say that they are rarely asked to feedback on their experiences, and that they lack opportunities to raise issues when care could be improved. NHS staff often lack the time or support to gather and act on feedback about the service, although there are positive examples of services that have made this a priority, such as the services at the Victoria Day Hospital and at Stobhill Hospital in Glasgow. There are long standing issues around people fearing the consequences of raising complaints about care because they depend on services. Anonymous feedback mechanisms such as Care Opinion provide a positive opportunity for individuals to engage, but are little known by the public.

**Varied experiences with NHS Boards – NHS Greater Glasgow and Clyde, NHS Ayrshire and Arran and NHS Grampian**
Parkinson’s UK has experienced major variations in the quality of engagement between different NHS Boards. We have concerns about the quality of the engagement and consultation carried out by NHS Greater Glasgow and Clyde about the proposed closure of Lightburn Hospital, which is viewed as an essential local resource in the East End of Glasgow.

Over 300 people with Parkinson’s use the Parkinson’s service based at the hospital. The Board had previously attempted to close the hospital in 2010. 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.

We have some concerns about the consultation exercise that the Board conducted. For example, the Board’s options appraisal exercise rated different options for the Parkinson’s service, but nobody affected by Parkinson’s took part in it. It is concerning that the Board believed it could rank the different location options for a service without involving the people who use it.

We are also concerned that the Board’s travel analysis did not reflect people’s real life experiences in an area with very low car ownership. Critically, the travel analysis did not refer to the fact that most buses do not stop within the Stobhill hospital site, and require a 15 minute or more walk up a steep hill to access the facilities.

In the absence of a relationship between people using the local Parkinson’s service and NHS Greater Glasgow and Clyde, Parkinson’s UK carried out a consultation meeting with 33 people with Parkinson’s and unpaid carers to explore the issues around different hospital sites. We submitted this to the Board, and note that the Board has decided to site the Parkinson’s service in Glasgow Royal Infirmary if the Lightburn closure goes ahead, reflecting the preferences expressed by people who use the service. However, we are 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 systematically captured. 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.

There are significant capacity issues within the Parkinson’s service in NHS Ayrshire and Arran, where 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.

While the North Ayrshire Health and Social Care Partnership has been engaging with local people and 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 pointless if agencies are unable to take action.

We found NHS Grampian and the Moray Health and Social Care Partnership to be willing to work with us, and with local people affected by Parkinson’s, when a staffing crisis left 250 people in Moray with no local access to a consultant or Parkinson’s specialist nurse. 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 locally.
3. Do services treat people with dignity and respect?

**Parkinson's specialist services**

Our Parkinson's UK Audit data suggests that amongst people whose Parkinson’s service participated in the audit, people with Parkinson’s and unpaid carers feel involved in care decisions and listened to by those providing Parkinson’s care services – 71.4% said they were always or mostly involved in clinical decisions, and 84.7% said they were listened to by their team.

However, our UK-wide Your Life Your Services Survey duplicated these questions, and its respondents were not necessarily attending the services that had “opted in” to take part in our audit. The picture was markedly worse - only 63.7% believed that their Parkinson’s team always or mostly involved them in decisions about their care and treatment, and 69.4% said they were always or mostly listened to by their team.

Participation in the audit is likely to be highest amongst those Parkinson’s services that are most motivated to improve their services, and comparing these datasets supports the view that where services have a focus on improvement, people are treated with greater dignity and respect. This raises questions about how the NHS can support an improvement culture across all services so that everyone can be expected to be treated with dignity and respect.

**Wider issues within NHS Scotland**

There are particular concerns about hospital care for people with Parkinson’s, because of issues around medication management and lack of staff understanding about the fluctuating nature of Parkinson’s and its range of symptoms.

Some of the stories that people have told us about their experiences in hospital particularly highlight negative encounters with staff, who sometimes fail to listen to people with Parkinson’s and unpaid carers about what they need.

One person with Parkinson’s who was admitted to hospital in NHS Forth Valley with a broken hip said:

“Some of the nurses were rude and unpleasant - they would tell me off as though I were a five year old. I felt like I had completely lost my dignity. I didn’t feel able to speak out. It was horrendous.”

Another person who was admitted to hospital in NHS Greater Glasgow and Clyde reported:

“I repeatedly explained to the nursing staff that I needed to get my Parkinson’s medication on time, because I wouldn’t be able to move without it. It was incredibly distressing to keep having to ask and tell the nurses what I needed. I was really upset one day when a trained nurse told me that I could move “when I wanted to.” I tried to explain that when I couldn’t move it was because of the medication, not me being difficult. There was a similar issue with some care assistants, where the way they treated me was so bad that three other patients in the surrounding beds complained on my behalf.

“Some of the younger nurses understood and did their best, but I was told more than once that, ‘We are very busy. You will get your medication when
we have time to give it to you.’ A lot of the nurses didn’t seem to know anything about Parkinson’s or the medicines that treat it.”

Another woman who was admitted in NHS Grampian, described being “dragged” to the toilet by a nurse when they were unable to move because their Parkinson’s medication was not working.

In contrast, some people report much more positive experiences, usually when they have a planned admission staff have had the opportunity to consider how to accommodate the person’s Parkinson’s within their care plans.

People report much better experiences when they are permitted to self-administer their Parkinson’s medication like they do at home, which enables them to control their ability to move and function. Unfortunately, progress towards enabling people to self-administer their Parkinson’s medication in hospital is very slow, with few wards in Scotland enabling this to happen routinely. Parkinson’s UK believes that it is essential that people who wish to administer their own Parkinson’s medication, and are able to do so, are enabled to do so.

4. Are staff and the public confident about the safety and quality of NHS services?
In general, we believe that people feel confident about the NHS. However, those who have experienced poor care in the past can have a lifelong aversion to returning to hospital.

We do not feel qualified to speak for NHS staff in general, although we know that many Parkinson’s nurses spend a lot of time supporting people with Parkinson’s who have been admitted to hospital and ensuring that the staff looking after them are aware of the need for them to receive their Parkinson’s medication on time, both for individual patients and also with training and other initiatives for ward-based colleagues.

5. Do quality of care, effectiveness and efficiency drive decision making in the NHS?
Parkinson’s UK recognises that most NHS professionals and managers want to work in a system that delivers high quality care and is effective and efficient. However, at times these principles are not appropriately balanced, and the drive to deliver short term or immediate efficiencies actually compromises the delivery of all three objectives. This is a particular risk when funding is short.

One example is that reduced ward staffing puts high strain on nurses and support staff, which can make administering medication outwith scheduled drug rounds very difficult. The impact of this is that inpatients with Parkinson’s become much more difficult to care for, because they may not be able to self-mobilise to go to the toilet, or to eat, and may experience disturbing psychotic symptoms. They also need to spend longer in hospital than if they were getting their medication on time.

Another example is reducing the amount of support that people with Parkinson’s receive from a Parkinson’s consultant or specialist nurse. This risks people not
receiving the optimum treatment for the Parkinson’s, which increases the risk of an emergency hospital admission or a premature move to a care home.

6. Are the correct systems in place to detect unacceptable quality of care and act appropriately when things go wrong?
One of the key issues for people with Parkinson’s who receive poor care in hospital is that most generalist professionals are unable to identify where a problem may have arisen as a result of failing to administer medication on time. People may assume that the person’s deterioration is caused by their condition itself, rather than poor quality care. This means that Parkinson’s medication errors are underreported and that action is often not taken.

**About Parkinson’s**
More than 11,000 people in Scotland people 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. 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’.

**About Parkinson’s UK in Scotland**
We’re the Parkinson’s charity that drives better care, treatments and quality of life. Together we can bring forward the day when no one fears Parkinson’s.