Technology and Innovation in the NHS
Parkinson’s UK in Scotland

1. What do you consider have been the main successes of the existing Scottish Government’s eHealth and telecare/telehealth strategies and why?

Parkinson’s UK welcomes progress made in a number of key areas as a result of the Scottish Government’s eHealth and telecare strategies. These include:

- Work on data linkages that has enabled the development of SPIRE
- The development of the electronic key information summary (e-KIS)
- The emergence of telemedicine for people living in remote and rural communities, including the islands

2. What do you consider have been the main failures of the existing Scottish Government’s eHealth and telecare/telehealth strategies and why?

Parkinson’s UK is concerned that previous decisions to release the majority of eHealth funding to individual NHS Boards has led to significant inequalities in provision and coverage of eHealth across the country. There are also issues of NHS structure and funding that have impeded technological innovation, as the following examples show:

Alerting Parkinson’s specialist team when a person with Parkinson’s is admitted to hospital

In 2011, NHS Healthcare Improvement Scotland recommended that Boards should: “develop an automated system to alert the neurology service when a Parkinson’s disease patient is admitted to hospital, and initiate systems to specifically identify and regulate Parkinson’s disease medication administration.”

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. Issues with Parkinson’s medication are often not understood by non-specialists, and the medication cause of a person’s deterioration is often not identified unless Parkinson’s specialists are involved.
This is a major problem for people with Parkinson’s in hospital. Data from the UK Parkinson’s Audit in 2015\(^1\) corroborates recent figures from a Scottish NHS Board\(^2\) showing that people with Parkinson’s receive their medication on time less than half of the time when they are in hospital. This leads to longer hospital stays, and considerable anxiety and distress for people with Parkinson’s and their families.

Yet for over five years, there was very little progress. It was left to clinicians and managers in individual NHS Boards to action the recommendation within their existing work programmes. With different IT systems being used in different NHS Boards, it was much harder to share information and good practice.

It is only in 2017 that resources have been made available to investigate the implementation of a consistent system across NHS Scotland, and this is being pursued via the National Advisory Committee for Neurological Conditions (NACNC), and we are very hopeful that this will result in a positive change that will have a meaningful impact on future inpatients with Parkinson’s.

The complex and fragmented eHealth landscape appears not to have been helpful in enabling clinicians and managers with Boards to deliver this much-needed change.

**Rollout of electronic prescribing in acute settings**

Given the documented advantages of electronic prescribing in hospitals, it is extremely disappointing hat only NHS Ayrshire and Arran has yet introduced it, suggesting that it has been given a low priority by other NHS Boards.

**Rollout of telemedicine**

While telemedicine can be transformative, our experience is that it is not frequently offered to people with Parkinson’s.

We know that there are about 100 people in the Northern Isles with Parkinson’s. They can only access specialist Parkinson’s services in Aberdeen. While limited telemedicine clinics are offered, very few people access this. Others go without specialist support or must face lengthy journeys to the mainland for appointments. We do not believe that technology is the problem here. Rather, it appears that the problem may be in contractual issues – such as the lack of detail about the service level agreements between NHS Orkney and Shetland and NHS Grampian.

In other remote areas, including Highland, Moray, Borders and Dumfries and Galloway, we are not aware of telemedicine being used to access appointments with Parkinson’s specialists.

**Rollout of e-PCS and e-KIS**

The palliative care needs of people with Parkinson’s are often not recognised, and we believe that the rollout of the electronic palliative care summary (e-PCS) and Key Information Summary (e-KIS) demonstrates some issues with technology rollout.

Different boards moved at very different speeds – and NHS Borders did not use e-PCS at all. While there is increasing take up of e-KIS, there remain significant geographical variations, and we suspect that many GPs remain unaware that people with Parkinson’s would benefit.
Any effective electronic system is dependent on the data that is fed into it, and unfortunately the existence of e-KIS in itself can neither make GPs complete it, nor health professionals access it.

We remain concerned that the important information contained in the e-KIS is still not accessible to key health professionals in secondary care once a person is admitted, including pharmacists. Issues of compatibility of electronic systems and information governance remain to be addressed.

**Exposure to cyber-security threats**
It is of concern that NHS Scotland was affected by the recent Wannacry ransomware virus, although not to the same extent as NHS England. Even though the attack affected only an estimated 1% of NHS Scotland machines, it undermined public and professional confidence in the use of eHealth.

Given the increasing dependence on eHealth, it is essential that all measures are taken both to protect people’s confidential health records and the system itself from malicious attacks.

**5. What key opportunities exist for the use of technology in health and social care over the next 10 years?**
Parkinson’s UK is very excited about the potential for technology to transform the care and support available for people with Parkinson’s and carers and for Parkinson’s research.

**Telemedicine**
Parkinson’s UK is extremely interested in the use of Attend Anywhere or similar technology to enable people with Parkinson’s to attend appointments with their specialists without having to travel long distances. We believe that this could be particularly helpful for those who live in more remote and rural settings, those who live in care homes and especially those whose Parkinson’s is very advanced. People in these groups are at very high risk of losing contact with their Parkinson’s team because it is so difficult to get to hospital clinics, leaving individuals and carers very isolated and without support to manage their symptoms and medication optimally. In light of this, we were disappointed to hear at a recent conference that some Boards were not planning to introduce this.

We have been very interested to learn about how NHS Western Isles is using robots and an adapted flat to enable people to undergo remote assessment and appointments. This service has great potential, and we know that some people have really appreciated using it. However, we are aware that some people – especially those with cognitive issues arising from their Parkinson’s – did not find this helpful.

**Apps and wearables**
Using apps and wearables is a growing area for people with Parkinson’s, and some people with Parkinson’s have expressed their frustration that clinicians do not recommend these routinely as part of a package of available support. We already know about apps that can help people with their speech, to overcome freezing, to monitor activity and record a range of symptoms, but the possibilities are endless.
Recently, the BBC programme the *Big Life Fix*[^1] showed how a designer from Microsoft worked with Emma Lawton, a graphic designer whose Parkinson’s tremor had left her unable to write or draw. The result was the “Emma watch,” which enabled her to write again. There are other wearables which are helping people to overcome tremor as well as monitoring physical activity via eg pedometers or fitness bands.

We are very interested in enabling data from wearables to be analysed by clinicians to enable them to identify when a person’s Parkinson’s may be deteriorating or a medication change could be needed. We would emphasise that this should be used to inform clinical practice, rather than be a substitute for it, especially because as Parkinson’s progresses, it is often necessary to balance the impact of medication on physical function with the need to improve cognition and mental health.

This is a very rapidly developing area. Parkinson’s UK is developing a system to enable us to recommend the use of certain apps and wearables where they have proven benefits for people with Parkinson’s.

Members of our Inverclyde Support Group have been using the [World Walking](https://www.worldwalking.co.uk) website and simple pedometers to increase their levels of physical activity. Everyone in the group counts their own steps and sends totals to one person who logs them on the world walking system. Most people put the pedometer on when they get dressed and keep it on until they go to bed, and find it a really good way of assessing how active they have been.

By pooling their steps, members have completed the Queen’s Baton Relay, walked from John o’Groats to Land’s End, the West Coast of Ireland, and the Northern 500. They also contributed to the [Million Miles Challenge for Inverclyde](https://www.millionmiles.org.uk). They have no doubt that it has encouraged them to maintain their activity levels.

**Data and research**

We are excited by the potential offered by new systems such as [SHARE](https://wwwSHARE.org.uk) and [SPIRE](https://www.spireregistry.org) to transform Parkinson’s research. They will both provide new access for researchers and could offer people with Parkinson’s new opportunities to participate in research, which is important to many.

Collecting data from wearables and apps has huge potential to enable the impact of drugs, surgery and other interventions to be measured.

**7. What are the barriers to innovation in health and social care?**

**Fragmented Working**

As outlined above, Parkinson’s UK would identify that the system of fragmentation between NHS Boards has been a barrier to achieving innovation. It has been difficult for clinicians to get the support that they need to achieve changes in practice around eg data collection, alerts and information transfer, partly because they are not always able to access support to enact the work.

We are concerned that systems may not be able to cope under the additional issues that will arise as a result of integration.
Information Governance
While there are real and important issues around protection of confidentiality, we are concerned that these could be holding up important changes that could improve care. We need to get the balance right between protecting privacy and enabling data to be shared between professionals who need it. Project such as the e-KIS suggest that we are not yet getting this balance right in Scotland.

Funding
In addition to wider funding issues in the NHS, there are major issues with funding for technological support. For example, it is estimated that 23% of all the need for assisted and augmentative technology (AAC) for speech is accounted for by people with Parkinson’s, but it is relatively rare for people to be referred for AAC. There are major issues with accessing funding to supply AAC equipment. If funding is not available, staff may be very reluctant to suggest that people use their own money to purchase equipment, particularly when individuals are on very limited incomes.

Staff training and support
There are also issues with staff training and familiarity with technology. Professionals lack time for training on new technologies and may not feel confident to recommend using them or recommending them for use by individuals that they support.

Digital infrastructure
Importantly, there are areas of Scotland that continue to lack decent broadband or mobile phone connectivity, and this must be resolved. Even where technology is widely accepted and used, it is important to recognise that technology can sometimes fail, and people must be able to access the care that they need if the technology does not work.

Digital literacy and personal preferences
It is important to be aware of issues around digital literacy and personal preferences which may impact on the willingness and/or ability of individuals to take up the opportunities offered by technology.

Although many older people are confident users of digital technology, and the proportion of older people who use digital communication is increasing rapidly, it’s important to note that this can be challenging for people who are not familiar with it. Some people do not wish to engage with digital technology at all, and some types of impairment make it very difficult.

Latest ONS statistics show that over half of all people over 75 (51.9%) and nearly a fifth (18.6%) of those aged 65 – 74 have never used the internet. Overall, more than a quarter of all disabled people – 27.4% - have never been online. This is a significant cohort of people – and particularly of those people who have the greatest need of healthcare. It is essential that they are not left behind in the process of digital transformation.

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.

Find out more about us at [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

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2 Unpublished data from NHS Board
3 The Modern Outpatient Conference, Heriot Watt University, 14.02.2017
4 [http://www.bbc.co.uk/news/av/magazine-38208814/the-invention-that-helped-me-write-again](http://www.bbc.co.uk/news/av/magazine-38208814/the-invention-that-helped-me-write-again)