

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

GET IT ON TIME

Get It On Time – the case
for improving medication
management for Parkinson's





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Introduction

What is Parkinson's?

We estimate there are 145,000 people living in the UK with Parkinson's.¹ By 2025, we expect the number of people with Parkinson's will rise by nearly a fifth to 168,582. And by 2065, it is expected to have doubled – due to an ageing population.

While the majority of people develop Parkinson's symptoms after the age of 65, thousands of working-age people are also affected. Parkinson's is a progressive, fluctuating neurological condition that affects all aspects of daily living including talking, swallowing and writing. Every person's symptoms are different.

People with Parkinson's often find it hard to move freely. There are also other issues such as pain, depression, anxiety, dementia, freezing, hallucinations, and continence problems. The severity of symptoms can fluctuate from day to day and people can experience rapid changes in functionality over the course of the day.

There is no cure for the condition, but medication can help people manage their symptoms. However, these regimes can be complex and, over time, medication can become less effective at controlling symptoms.

Importance of medication

If people with Parkinson's don't get their medication on time it can seriously impact their health. They may not be able to move, get out of bed, swallow, walk or talk. Some people may

never recover and may permanently lose their ability to walk, talk or worse.

Even a delay in taking medication of 30 minutes can lead to serious health implications for someone living with Parkinson's. In 2017, NICE recognised the importance of levodopa admission as an area for quality improvement within the Parkinson's NICE quality standard.²

The average person living with Parkinson's may find themselves on nine doses of medication a day.³ The timing of these medications alters from person to person and often doesn't correspond with typical medication rounds on hospital wards. This is because everyone's Parkinson's symptoms are different and therefore need different medication management regimes.

As a result, people with Parkinson's often miss out on their vital medication while staying in hospital for reasons unrelated to Parkinson's. This happens because someone with Parkinson's will often be treated on a general medical ward – rather than a specialist neurological ward – for ill health unrelated to their condition. This makes missed medication more likely as staff on these wards do not have an in-depth knowledge of Parkinson's.

Not only does this have hugely adverse effects on people's health – keeping them in hospital longer – it also costs the NHS extra money. This is because a person who could already have been discharged needs to be looked after longer.

¹ Parkinson's UK. Parkinson's diagnoses set to increase by a fifth by 2025 [Internet]. 2018 [cited 16 July 2019]. Available from: <https://www.parkinsons.org.uk/news/parkinsons-diagnoses-set-increase-fifth-2025>

² NICE. Quality standard: Parkinson's disease [Internet]. 2018 [cited 16 July 2019]. Available from: <https://www.nice.org.uk/guidance/qs164/resources/parkinsons-disease-pdf-75545600441029>

³ Grosset D et al. Adherence to antiparkinson medication in a multicenter European study [Internet]. 2009 [cited 16 July 2019]. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/19191340>

The Parkinson's UK Get It On Time campaign calls on all UK hospitals and care homes to ensure every person with Parkinson's receives their medication on time, every time.

Although the campaign has been running for a number of years, we've seen little progress. Unfortunately, we're still hearing harrowing stories about people going into hospital and coming out more unwell than they were before they went in.

It is vital this changes. That's why we're calling on every hospital in the UK to take responsibility and provide the care and support people with Parkinson's should expect.

We're also aware this is an issue for people with Parkinson's in care homes, and in future years we will focus attention on this setting.

This report contains data from a UK-wide freedom of information request to trusts and health boards, our 'Get It On Time' survey of people with Parkinson's and carers, and our annual 'Your life, your services' survey. The report data and recommendations cover the whole of the UK.

Throughout the report, we will refer to health bodies as trusts and health boards to reflect the different healthcare systems across the UK.

We will also evaluate each of the following areas that represent recurring issues around medication management for people with Parkinson's admitted to hospital:

Knowledge – education and support for health professionals

Self-administration – allowing people, if able, to take their own medication

Monitoring – systems that enable hospitals to improve medication management practice

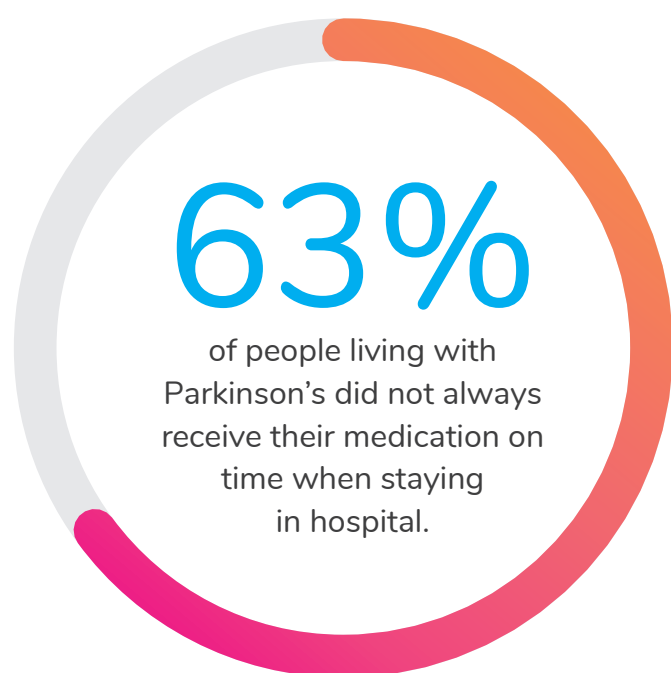
Specialist input – alerting specialists when someone with Parkinson's is admitted to hospital



Executive summary

Key problems

Parkinson's UK believes too many hospitals in the UK are failing people living with Parkinson's. Pressures on nurses and ward staff due to staffing shortages (40,000 nurses in NHS England alone⁴) have contributed to a failure to provide patients' basic needs, such as timely doses of medication. However, even with capacity issues, the NHS in England, health boards in Wales and Scotland and health and social care trusts in Northern Ireland must eradicate simple problems that contribute to poor medication management in hospitals. Each excess bed day in a hospital costs a trust or health board an average of £346, in addition to the £1,603 average admission cost. Evidence indicates that people with Parkinson's stay in hospital longer if they miss medication. We have heard stories of people regularly having their discharge delayed by two weeks or more.



A two-week delay would cost the NHS £4,844 a patient – a waste of NHS resources.⁵

The latest data shows that people with Parkinson's face 28,860⁶ excess bed days in hospital every year in England alone – this costs the NHS £10m a year. While not all of these excess bed days are from poor medication management, we know missed medication makes a large contribution to staying in hospital longer.

To provide an accurate picture of what is going wrong in hospitals, we've gathered evidence from across the UK. We have done this using a freedom of information request sent to all hospital trusts in England, health boards in Wales and Scotland, and health and social care trusts across Northern Ireland. We have also surveyed over 700 people affected by Parkinson's to hear their views and experiences specifically

⁴ NHS England. Interim NHS People Plan [Internet]. 2019 [cited 17 July 2019]. Available from:

https://www.longtermplan.nhs.uk/wp-content/uploads/2019/05/Interim-NHS-People-Plan_June2019.pdf

⁵ NHS England and NHS Improvement. Reference costs 2017/18: highlights, analysis and introduction to the data [Internet]. 2018 [cited 17 July 2019]. Available from https://improvement.nhs.uk/documents/1972/1_-_Reference_costs_201718.pdf

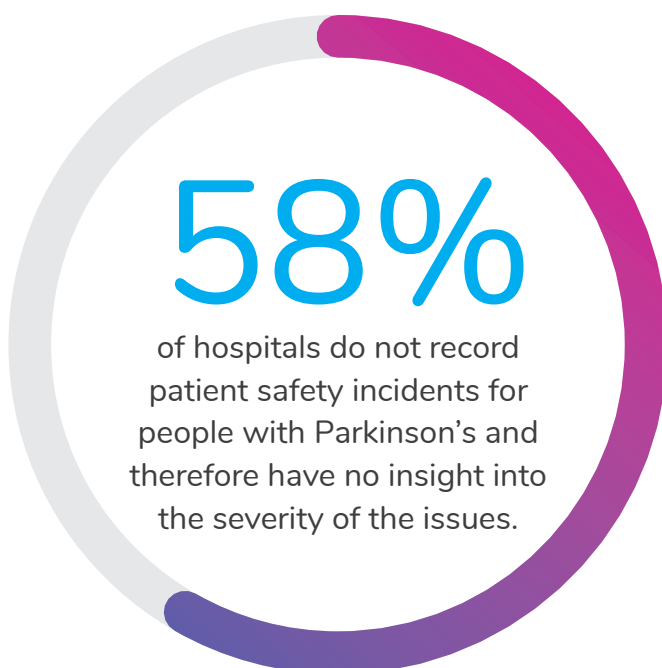
⁶ Excellence Network Data Dashboard [Internet]. 2019 [cited 12 August 2019]. Available from:

<https://www.parkinsons.org.uk/professionals/resources/excellence-network-data-dashboards>

on Get It On Time,⁷ as well as using data from our annual 'Your life, your services' survey.⁸

Our findings confirm that too many people with Parkinson's are not receiving their medication on time, every time:

- 63% of people living with Parkinson's did not always receive their medication on time when staying in hospital.
- 657 patient safety incidents relating to missed Parkinson's medication were reported from just 47 hospitals in the financial year 2018/19.
- One hospital reported 97 patient safety incidents within this timeframe.
- 58% of hospitals do not record patient safety incidents for people with Parkinson's and therefore have no insight into the severity of issues within the trust or health board.
- Only 44% of trusts and health boards offer ward staff mandatory training on Parkinson's.



- 57% of trusts and health boards do not have a system that alerts specialist professionals when a person with Parkinson's is admitted to one of their wards.
- Many trusts and health boards have out-of-date self-administration policies that mean people with Parkinson's able to take their own medication are unable to do so, with a further 26% of trusts having no policy at all.
- 31% of trusts and health boards are either unaware of – or not using – Parkinson's UK learning and ward resources to support successful medication management.



⁷ See appendices 1-3 for more information on these surveys and the freedom of information requests.

⁸ Parkinson's UK. Your life, your services survey [Internet]. 2018 [17 July 2019]. Available from: <https://www.parkinsons.org.uk/news/parkinsons-2018-your-life-your-services-survey>



Recommendations

To ensure that people with Parkinson's always receive their medication on time, we are calling for the following changes in the UK:

- ✓ Every hospital trust and health board should implement mandatory training on Parkinson's for all hospital staff. This must include the UK Parkinson's Excellence Network's 15-minute narrated PowerPoint on medication management.
- ✓ Every hospital trust and health board must have a self-administration policy that is in date and enables people with Parkinson's to take their own medication if they are able to do so. Any policy must be supported by the correct hospital facilities, staff training, resources for patients and regular monitoring on how the policy is used.
- ✓ Every hospital trust and health board must record patient safety incidents by condition to improve reporting on missed medication doses for people with Parkinson's. This will provide data that will support improvement around medication management practice.
- ✓ Every hospital trust and health board must record any occasion when the administering of Parkinson's medication is delayed by more than 30 minutes as a patient safety incident.
- ✓ Every hospital trust and health board should use a system that alerts specialist Parkinson's professionals when someone with Parkinson's is admitted to a ward in their hospital.

In addition, we are calling for the following in England:

- ✓ The Care Quality Commission should make a missed dose of Parkinson's medication a 'Never Event'. A Never Event is an incident with the potential to cause serious harm to a patient but which is wholly preventable. Making a missed dose of Parkinson's medication a Never Event would boost awareness and reporting.

Survey findings

Parkinson's UK conducted a survey of over 700 people affected by the condition to hear about their experiences on medication management. This survey uncovered the huge impact not receiving medication on time can have on people living with Parkinson's.

- 63% of survey respondents told us they had been admitted to hospital in the last year.
- Only 21% of respondents told us they received their medication on time without having to remind hospital staff.
- 47% were not given the option to administer their own medication, and a further 12% were not always able to do this due to varying practices among health professionals.
- 78% of respondents told us their health got worse as a result of not receiving their medication on time.



Getting medication on time:

“Even though I stayed with my husband his Parkinson's medication was locked away. I have administered his pills for the last four years owing to dementia and found it very upsetting when I was told often that the trolley would be around 'in a minute' which could be up to half an hour.”

“We complained constantly about this – they were so busy and would not give it till they did the drugs rounds. This was not adequate. Mum was not allowed to medicate herself even though she was capable.”

“As someone well able to assert himself, I managed one way and another to keep my meds most of the time, having a debate with the various nursing sisters involved. But many people could not do this and none of us should have to.”

“My dad is often in hospital as a result of falls in his home. The hospital pretty routinely are unaware of his medication if it's not taken in with him, and of the importance that it is administered at the same time each day. He will normally be out of his medication routine within hours of being in the hospital.”

Adverse health outcomes:

“

I went into a panic and started shaking uncontrollably.”

“

Loss of mobility.”

“

Agitated.”

63%

of survey respondents
told us they have been
admitted to hospital in
the last year.



Self-administration:

“ This depended on the sister in charge of each shift. No one was aware of a hospital policy on this.”

“ No! Because the ward sister insisted it be locked away.”

“ Originally the nursing staff took my medication for them to dispense. However, after a visit from the pharmacist, it was returned for me to control.”

“ Some of the wards allow self-medication – others do not.”

“ I asked, but they declined and kept all drugs locked away.”

47%

were not given the option to administer their own medication, and a further 12% were not always able to do this.



The problem: professional training

Many health professionals will only treat a handful of people with Parkinson's in their working careers. This means that often there isn't widespread awareness about the condition – one that affects 145,000 people in the UK.

It also means the NHS does not prioritise educating professionals in the condition or stressing the importance of medication to control symptoms.

Our freedom of information request shows that only 44% of hospital trusts or health boards provide formal mandatory training for professionals working on hospital wards. This is where medication mismanagement happens most often.

A further 19% of trusts and health boards told us that they provide ad hoc training as and when it is requested. While training is



welcomed, many trusts and health boards told us this only takes place when requested by health professionals. Often training will only be requested when a professional has treated someone with Parkinson's and something went wrong.

In addition, only 35% of trusts and health boards could provide figures on how many of their health professionals have received learning on Parkinson's.

The lack of data collection surrounding learning is concerning – we believe it must be systemised to ensure that universal coverage of training on Parkinson's takes place.

This approach does not reflect NHS England's focus on prevention, as set out in the *Long Term Plan*⁹ and green paper on prevention.¹⁰ Failing to prioritise professionals' learning on Parkinson's means more people will have



⁹ NHS England. NHS Long Term Plan [Internet]. 2019 [cited 19 July 2019]. Available from:

<https://www.england.nhs.uk/long-term-plan>

¹⁰ GOV.UK. Prevention Green Paper [Internet]. 2019 [cited 12 August 2019]. Available from:

<https://www.gov.uk/government/news/health-secretary-launches-prevention-is-better-than-cure-vision>

longer hospital stays, with a lack of preventative strategies to keep people well in their own homes.

The UK Parkinson's Excellence Network has a 15-minute narrated powerpoint presentation.

This provides professionals with the basic information they need to ensure they can support people with Parkinson's to take their medication on time.



Case study: Carole D's story

I went into Leighton Hospital in Crewe as a result of a chest infection and asthma. My husband and son got to the hospital before me and informed the staff that I have Parkinson's.

When I arrived at approximately 11.30am, I also told staff I had Parkinson's and would need to take my medication. My alarm went off at 1pm when I was due to take my medication but the nurse said she needed to have them checked before I could take them. My son intervened at this point and took them off the nurse so I could have them, telling her again how important it was for me to take my medication on time. The nurse seemed annoyed and took them away to be checked.

It got to 5pm and my alarm went off again but I still didn't have my medication. My husband asked about them and was told they still needed to be checked. Luckily I had an emergency set in the car so my husband fetched them for me.

The nurse came back at 5.50pm and said I could take them – she wasn't happy that I'd already had them. I was only in hospital a day as I knew I'd get better at home, but the worry over medication contributed to me not wanting to stay in any longer. I'm the patient and I know when I need my medication – the staff didn't seem to understand how important it is, regardless of how many times we told them.

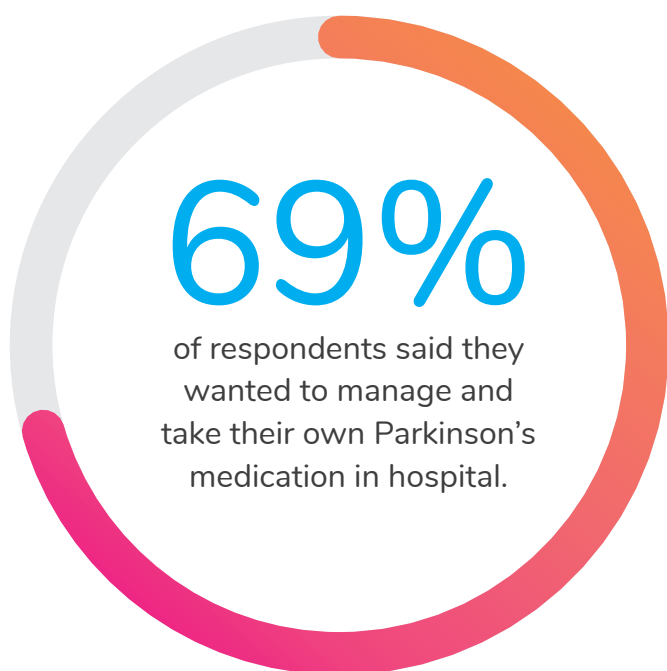
If I'd have waited for the nurse to come back, the medication probably wouldn't have kicked in for another hour and when I don't take my medication I can't move or I really struggle to get going. I was lucky my family were there or I'd have been stuck.

I didn't know but anyone can ask for the pharmacist to look over their medication, and I think this is worth telling people. If I'd have known I'd have asked for them straight away and would have been allowed to take my medication when I needed it."

Our ask

Every hospital trust or health board should implement mandatory training on Parkinson's for all hospital staff. This must include the UK Parkinson's Excellence Network 15-minute narrated PowerPoint on medication management.

The problem: self-administration



People with Parkinson's and their carers are often adept at taking their medication on time to manage their symptoms when outside a hospital setting. Therefore, if someone goes into hospital – often with an illness unrelated to Parkinson's – they should not have their right to manage their own medication taken away from them.

In 2018, we conducted our 'Your life, your services' survey. As many as 69% of respondents said they wanted to manage and take their own Parkinson's medication in hospital. Unfortunately, only 54% said it was possible for them to do so.

Our research has found that there is a big difference in the provision of self-administration of medication policies across the UK.

While 73% of trusts and health boards told us they had a self-administration policy, many said they did not routinely use this for people with Parkinson's.

A total of 59% of trusts and health boards that have a policy told us there is no audit of how the policy is used. This means there is a lack of evidence and knowledge on whether

self-administration policies are being used by people with Parkinson's, rather than people with other conditions such as diabetes.

A policy in each trust and health board is not enough to enable patients to administer their own medication. Hospitals must have the correct facilities, including lockable cupboards to store medication. They should train staff to assess whether people with Parkinson's are able to administer their own medication, with the ability to explain procedures and provide people with Parkinson's with the resources to support them.

We have heard of hospitals that have a self-administration policy but no lockable cupboards, making the policy defunct. We are also aware of hospitals that have a policy but don't feel it is appropriate for people with Parkinson's – demonstrating a lack of staff awareness and knowledge.

There is a lack of knowledge about self-administration in the Parkinson's community, due to a lack of promotion from hospitals. This must change to ensure people with Parkinson's are aware of the potential to take their own medication.





Case study: Paul's story

Paul from Bangor in Northern Ireland was diagnosed with Parkinson's nine years ago. Since his diagnosis, Paul has developed an interest in drawing and has become a very successful artist. He recently achieved his black belt in karate and is also a member of the NI Parkinson's community choir, Parsonik.

In 2018, Paul had two separate admissions to different hospitals in Belfast and two totally contrasting experiences of getting his Parkinson's medication on time.

"On the first occasion, I was admitted to hospital for investigations around a health concern that was unrelated to my Parkinson's and I was feeling worried and scared. I needed my Parkinson's medication at 12 noon but when I asked for it at that time, I was told the drug round was not until 1pm. No one on the ward was aware that people admitted with Parkinson's had to get their medication at very specific times. By the time I got my tablets, I couldn't even communicate. All my doses after were also then delayed."

Friends and family coming to visit Paul couldn't believe how much his condition was deteriorating. He says: "I had uncontrollable tremors, I couldn't do anything for myself, I literally couldn't function and I was immobile."

Three days after Paul was admitted, a nurse came on to the ward who had previously treated him.

He continues: "Finally, there was someone who knew how important it was for me to get my medication on time. I was given the opportunity to self-medicate at the proper times and was allowed to keep my tablets in a locker beside my bed. However, problems arose again because the locker was operated by a magnet that was held on to by the ward staff, and there was not always someone around to give the magnet to me."

It took Paul nearly a week to start to feel like himself again. He adds: "I was admitted to a different hospital in Belfast at a later date and the staff had completed the Parkinson's UK 'Get It On Time' training. It was a completely different experience and I got my medication on time, every time."

Our ask

Every hospital trust and health board must have a self-administration policy that is in date and that enables people with Parkinson's to take their own medication, if they are able to do so.

Any policy must be supported by the correct hospital facilities, staff training, resources for patients and effective monitoring on how the policy is used.

The problem: alert systems and specialist input

Most people living with Parkinson's will be under the care of specialist health professionals who understand their condition and are able to offer expert medical advice.

These professionals can include: consultants, neurologists, geriatricians, Parkinson's specialist nurses, and allied health professionals. However, when a person with Parkinson's becomes an inpatient due to a period of ill health, they will be cared for by different professionals who are not usually linked to the specialist team.

It is vital that when someone with Parkinson's is admitted to hospital the specialist team

are alerted. This enables them to offer input and specific knowledge about the patient, including vital information about their medication regime.

Unfortunately, we know that this is not happening everywhere in the UK. In fact, only 44% of hospitals have a system set up that alerts a person's specialist team when they're admitted to hospital.

Within this 44%, some alerts aren't instant and can take over 24 hours to reach the specialist team. In this time someone with Parkinson's could be receiving poor care and be in need of specialist input, particularly on the importance of medication timing.



Case study: Christine's story

Christine's husband was admitted to hospital for four to five days with vomiting, diarrhoea and dehydration. On his first night in hospital, Christine's husband phoned her up extremely agitated because the staff were not giving him his medication on time. He takes approximately 20 tablets for Parkinson's throughout the day – when he wakes, and at 11.30am, 3.30pm and 6.30pm. Although he usually administers his medication himself, the staff had taken all his tablets and were only administering them twice a day.

Christine phoned and talked a member of staff through her husband's medication regime. She also stressed how important it was that it was adhered to. After two days, she returned to find her husband was still not receiving his medication on time, so she printed two lists. She gave one to the nurse and left one by his bed. The next day she came back to find one list had been lost under a pile of papers and the other was still by his bed but was being ignored.

They were both extremely disturbed by the situation and are terrified about him going back to hospital or into a care home.

Our ask

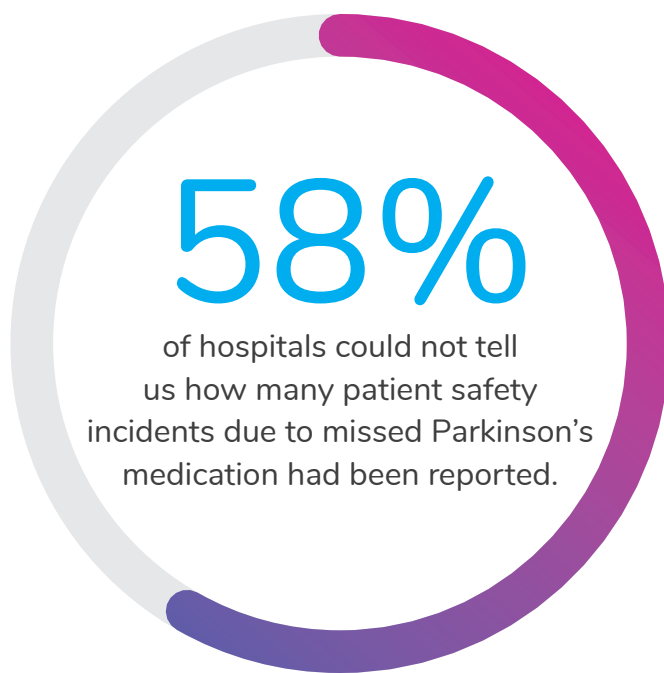
Every hospital trust and health board should use an alert system that can alert specialist Parkinson's professionals within two hours of a person with Parkinson's being admitted to a ward.





The problem: reporting

The scale of medication mismanagement for people with Parkinson's is hard to quantify due to poor reporting mechanisms within the UK's health systems.



It is unacceptable that 58% of hospitals could not tell us how many patient safety incidents due to missed Parkinson's medication had been reported. As many as 17% of these were because trusts and health boards have no shareable data on patient safety incidents at all. The other 41% of trusts and health boards have no data to share because they do not record patient safety incidents by condition.

In 2014, NHS Improvement launched a Patient Safety Thermometer in England,¹¹ aimed at improving reporting around missed medication dosages. Due to the high number of people with Parkinson's still not receiving their medication on time, it is clear this has been ineffective in improving care for people with Parkinson's.

In the financial year 2018/2019, there were 657 reported Parkinson's-related patient

safety incidents from the 47 hospitals able to provide data. This means, on average, each hospital has 14 patient safety incidents every year. If we assume there is similar care in the 58% of hospitals unable to give data, this suggests 1,565 patient safety incidents a year for people living with Parkinson's.

However, we also know that every hospital reports patient safety incidents differently, with the threshold of time and severity of missed medication to constitute a patient safety incident varying across the country. This means our estimate of 1,565 patient safety incidents does not accurately show the size of the issue.

The amount of patient safety incidents must reduce but, first, every hospital must ensure they have data in this area to understand the scope of the problem. Without the data, it is impossible for hospital trusts and health boards to understand how many people are missing their medication and how this can be rectified.



¹¹ NHS Improvement. The Medication Safety Thermometer [Internet]. 2013 [cited 18 July 2019]. Available from: https://www.safetythermometer.nhs.uk/index.php?option=com_content&view=article&id=3&Itemid=107



Case study:
Jane Alty,
Consultant
neurologist

Jane share how Leeds Teaching Hospitals NHS Trust improved medication management for people with Parkinson's:

"We had a case where a patient with Parkinson's was cared for in our trust for a period of time, during which there were frequent occasions when his Parkinson's medications were delayed or not given. This sadly contributed to a deterioration in his swallowing and his overall condition, as well as lengthening his time in hospital.

His wife wrote a letter outlining a number of solutions that could have made things better for her husband.

We also knew this was not a unique set of events, as audits and complaints previously had shown missed opportunities to deliver timely administration of medication.

This was taken on board by the trust, with a clear commitment to improve the service. Our overall objective was to ensure people with Parkinson's get their medication on time.

More specifically, we were going to monitor delays to first medications after admission, percentage of medications omitted and average delays to receiving medication.

We felt that to get solutions that would truly work in practice, we needed to utilise the expertise of different people across the trust – not just the ward staff and clinicians specialising in Parkinson's.

Therefore we, along with the carer, organised weekly multidisciplinary team meetings that could be attended by anyone.

What was amazing to see was the breadth of people coming along – everyone from IT managers, hospital porters, consultants and junior doctors to nurses, therapists, pharmacists and carers. And everyone had ideas about how they could help.

We created an intervention bundle, which consisted of resources such as an alarm clock and the Get It On Time laminated clock.

We came up with a six-monthly educational masterclass day, to which all staff are invited. And we also identified people who would collect data on each of these wards. This was then sent to the IT department who helped to create



some lovely improvement charts. We also had medical students review medical notes to gather retrospective data prior to the intervention.

So far, we have seen some dramatic results across the trust with the delay of the first medication on admission going down from over seven hours to below one hour.

The average percentage of Parkinson's medication doses omitted over a 24-hour period has also fallen, from 15% to 5%. Obviously we still want to improve things but this shows that the incredible effort of everyone has made a difference. The carer whose husband had a poor

experience has played an integral part in this project.

The fact she was able to take a bad experience and use it for something so positive is amazing. As a family, they feared the time he may need to go back to hospital and, although this did occur, they noticed a huge improvement.

The carer said that the culture in the hospital had completely changed from the previous time. She particularly noticed that the staff are a lot more knowledgeable about Parkinson's and she and her husband had much more confidence in the quality of care."

Our asks

- In England, the Care Quality Commission should make a missed dose of Parkinson's medication a Never Event. A Never Event is an incident with the potential to cause serious harm to a patient but which is wholly preventable. Making a missed Parkinson's dose a Never Event would boost awareness and reporting.
- Every hospital trust and health board must record patient safety incidents by condition to improve reporting on missed medication for people with Parkinson's. This will provide data for trusts and health boards that need the most support to improve.
- Every hospital must record any occasion when the administering of Parkinson's medication is delayed by more than 30 minutes as a patient safety incident

Resources and support from Parkinson's UK

Parkinson's UK has developed a number of resources – and support – for people living with Parkinson's and professionals to ensure medication management improves in hospitals.¹² These resources are used in many hospitals. But with 69% of trusts telling us they utilise the resources, there is still work to do to ensure every hospital trust and health board in the UK benefits from the support available.

Our resources include:

- the Get It On Time poster – designed to be displayed in hospital wards to improve staff awareness about how vital timing is for Parkinson's medication
- the Get It On Time laminated clock poster – can be placed by the hospital bedside of a person with Parkinson's to discreetly prompt staff to ensure they get their medication on time
- Get It On Time stickers – can be used to promote our Get It On Time campaign, but can also be used by professionals to add to patient notes and act as a useful reminder to give medicine on time
- the Get It On Time washbag – helps people with Parkinson's inform hospital ward staff that they need to take their medication on time. Includes tips on preparing for a hospital stay, a card to record medication, a laminated clock flyer to put by people's bedsides to prompt staff about their medication, stickers that can be put on hospital notes and a wallet-sized card to help staff understand more about Parkinson's
- medicines optimisation consensus statement¹³ – outlines the key medicine management issues people with Parkinson's face when admitted to hospital and highlights ways to manage these effectively (also includes supporting checklist, case for service change and audit appendices). One key issue is the need to get medication on time

These resources can all be ordered or printed from [parkinsons.org.uk/GIOTresources](https://www.parkinsons.org.uk/GIOTresources)

In addition to these resources, our helpline and local advisers are available to support people living with Parkinson's and family members on issues around medication management. Call **0808 800 0303** or email us at hello@parkinsons.org.uk

¹² Parkinson's UK. Get It On Time resources [Internet]. 2017 [cited 18 July 2019]. Available from:

<https://www.parkinsons.org.uk/information-and-support/get-it-time-resources>

¹³ Parkinson's UK. Medicines Optimisation Consensus Statement [Internet]. 2017 [cited 18 July 2019]. Available from:

<https://www.parkinsons.org.uk/professionals/resources/medicines-optimisation-consensus-statement>



Conclusion

People with Parkinson's who are admitted to hospital face an uncertain time, when they should feel safe knowing they will receive the care they need, no matter why they have been admitted.

It is vital people with Parkinson's adhere to their medication regimes, which often take time to perfect and is key to helping them manage their symptoms and live well with the condition.

Hospitals are a place people go to get better, not worse. Someone with Parkinson's not getting their medication on time can have a disastrous impact on their condition and waste NHS resources.

This is an issue that could affect anyone living with Parkinson's. We know some trusts and health boards have made improvements in this area and are now ensuring more people with Parkinson's are receiving their medication on time.

However, there is still a long way to go until a person with Parkinson's can go to any hospital in the UK and be confident that they will receive their medication on time, every time.



Case study: Carole B's story

I had to go into hospital after my knee gave way and I fell at home. Often you go into hospital with something unrelated to your Parkinson's but then your Parkinson's gets worse due to it not being managed properly.

While in the hospital I missed repeated doses of my medication due to a lack of knowledge and understanding of my condition-specific needs. This threw me out of sync completely – it brought on more severe depression, unsteadiness on my feet, more severe tremors. It affected me in so many ways.

It's impossible for me to control these symptoms, particularly my tremor, without my medication.

I am perfectly capable of taking my own medication. My husband, myself and my daughter all asked if I could do so on several occasions, however I was never allowed to.

I was ill and I just wanted to get better. I could have helped the hospital staff as I knew all about the medication I should have been taking.

The knock-on effects of missing my medication still affect me now, long since I have been at home. As well as affecting my health, the experience has affected my confidence and makes me terrified of going back into hospital. Going to hospital shouldn't have been such a battle for me to get better and go back home.



Recommendations

To ensure that people with Parkinson's always receive their medication on time, we are calling for the following changes in the UK:

- ✓ Every hospital trust and health board should implement mandatory training on Parkinson's for all hospital staff. This must include the UK Parkinson's Excellence Network 15-minute narrated powerpoint on medication management.
- ✓ Every hospital trust and health board must have a self-administration policy that is in date and enables people with Parkinson's to take their own medication if they are able to do so. Any policy must be supported by the correct hospital facilities, staff training, resources for patients and regular monitoring on how the policy is used.
- ✓ Every hospital trust and health board must record patient safety incidents by condition to improve reporting on missed medication doses for people with Parkinson's. This will provide data to support improvement around medication management practice.
- ✓ Every hospital trust and health board must record any occasion when the administering of Parkinson's medication is delayed by more than 30 minutes as a patient safety incident.
- ✓ Every hospital trust and health board should use a system that alerts specialist Parkinson's professionals when someone with Parkinson's is admitted on to a ward in their hospital.

In addition, we are calling for the following in England:

- ✓ The Care Quality Commission should make a missed dose of Parkinson's medication a 'Never Event'. A Never Event is an incident with the potential to cause serious harm to a patient but which is wholly preventable. Making a missed dose of Parkinson's medication a Never Event would boost awareness and reporting.

Appendices 1-3: evidence

Appendix 1: Your life, your services 2018

A yearly survey on the care people with Parkinson's and family members receive from the NHS.

Open between: August 2018 and October 2018

Responses: 2,903

Relevant question: Q16b. While in hospital, how often did you receive your Parkinson's medication on time?

Appendix 2: Get It On Time survey

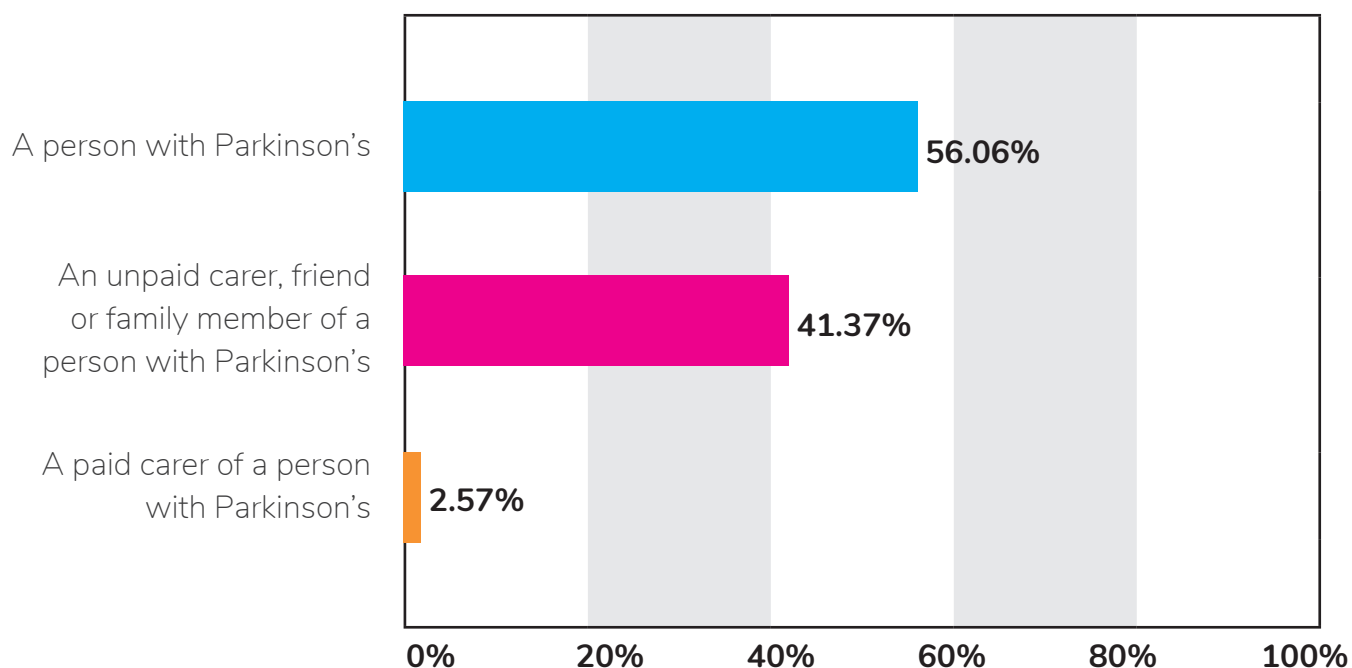
A one-off survey on the experiences of people with Parkinson's in hospital around medication management.

Open between: May 2019 and July 2019

Responses: 729

Questions and summary answers:

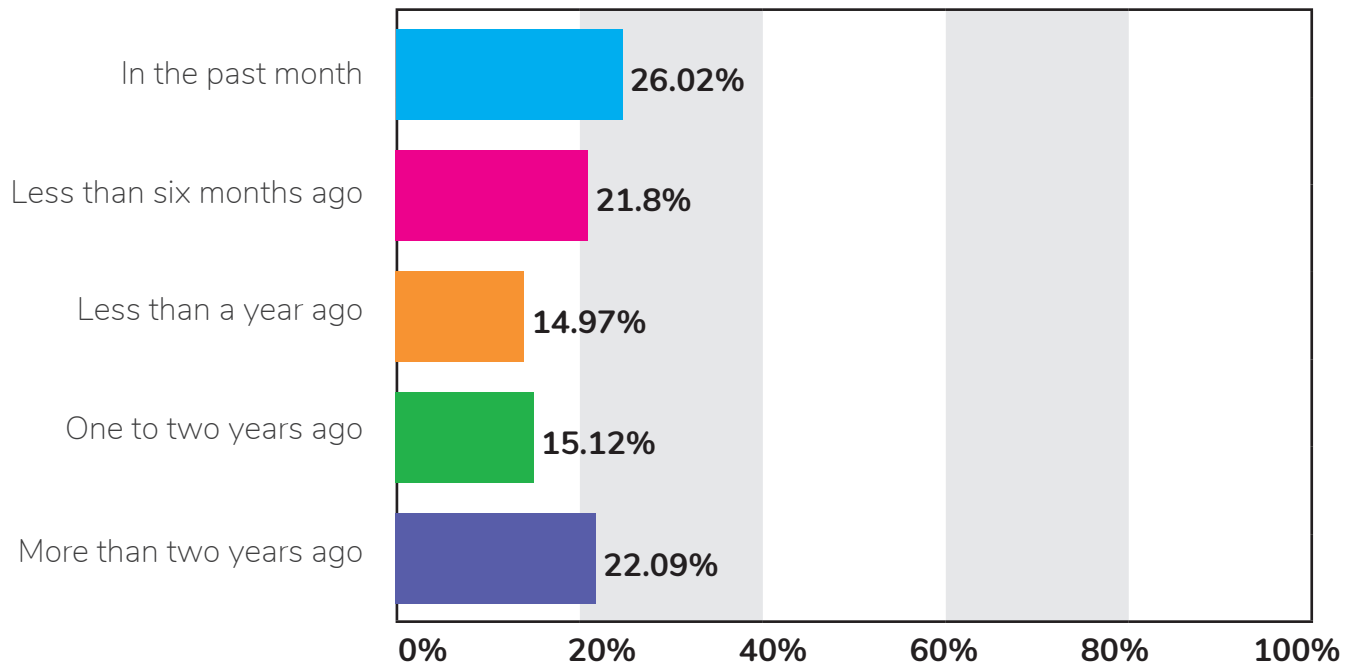
1. Which of the following best describes you?



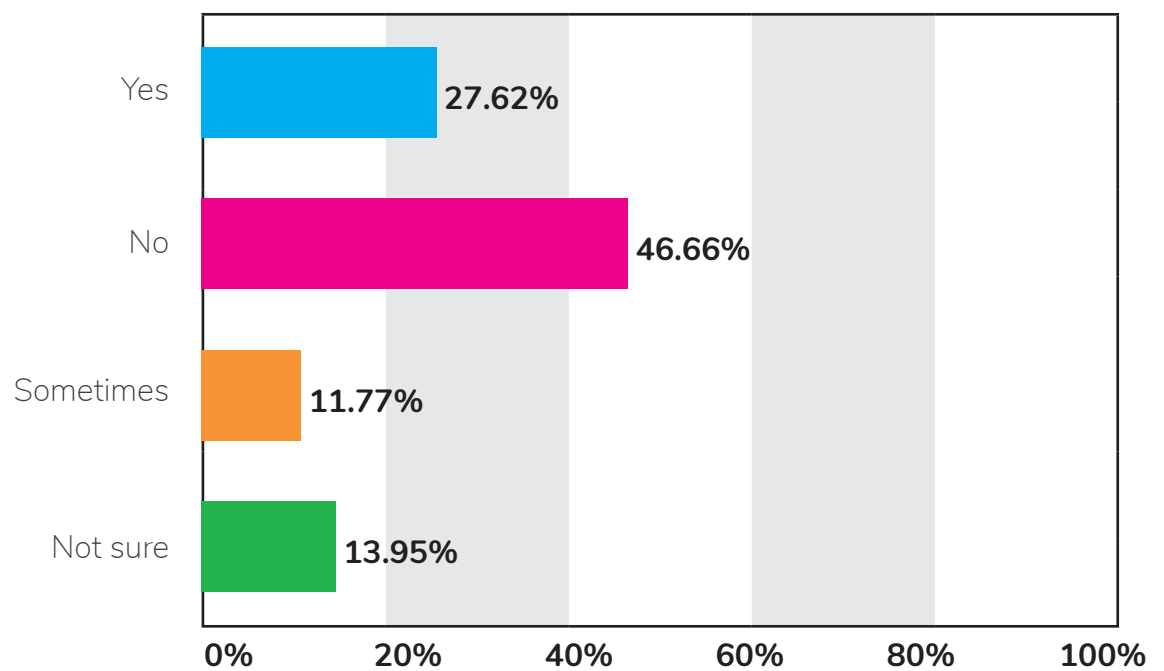
2. What's the name of your local hospital?

Raw data available on request.

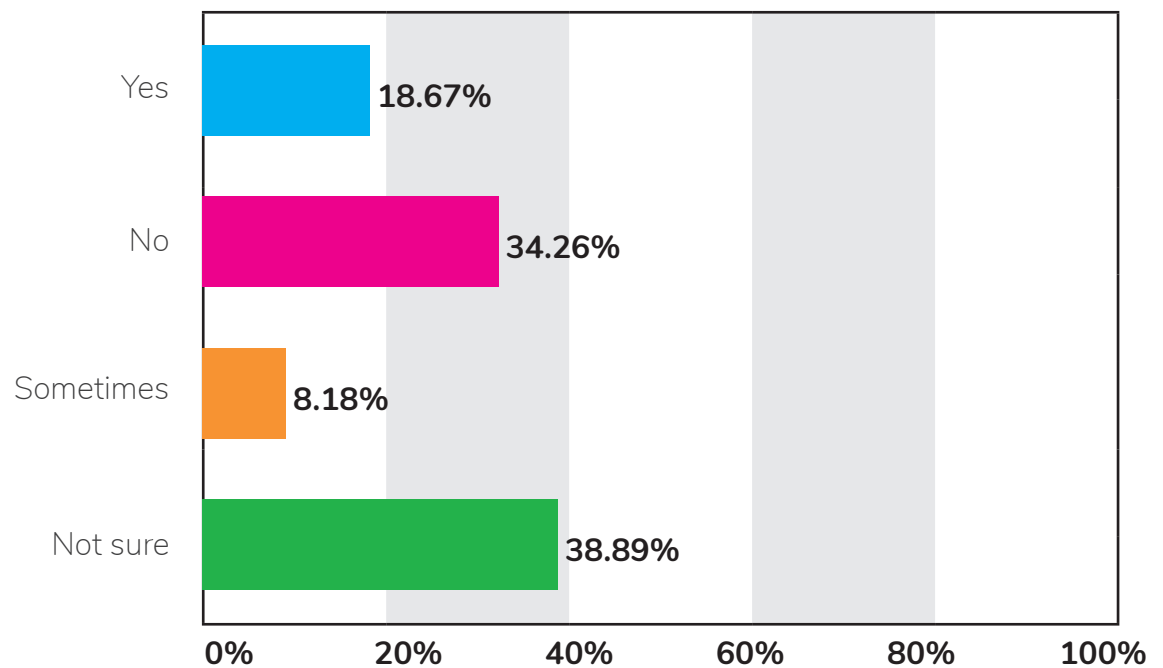
3. When was the last time you – or the person you care for – were admitted to your local hospital?



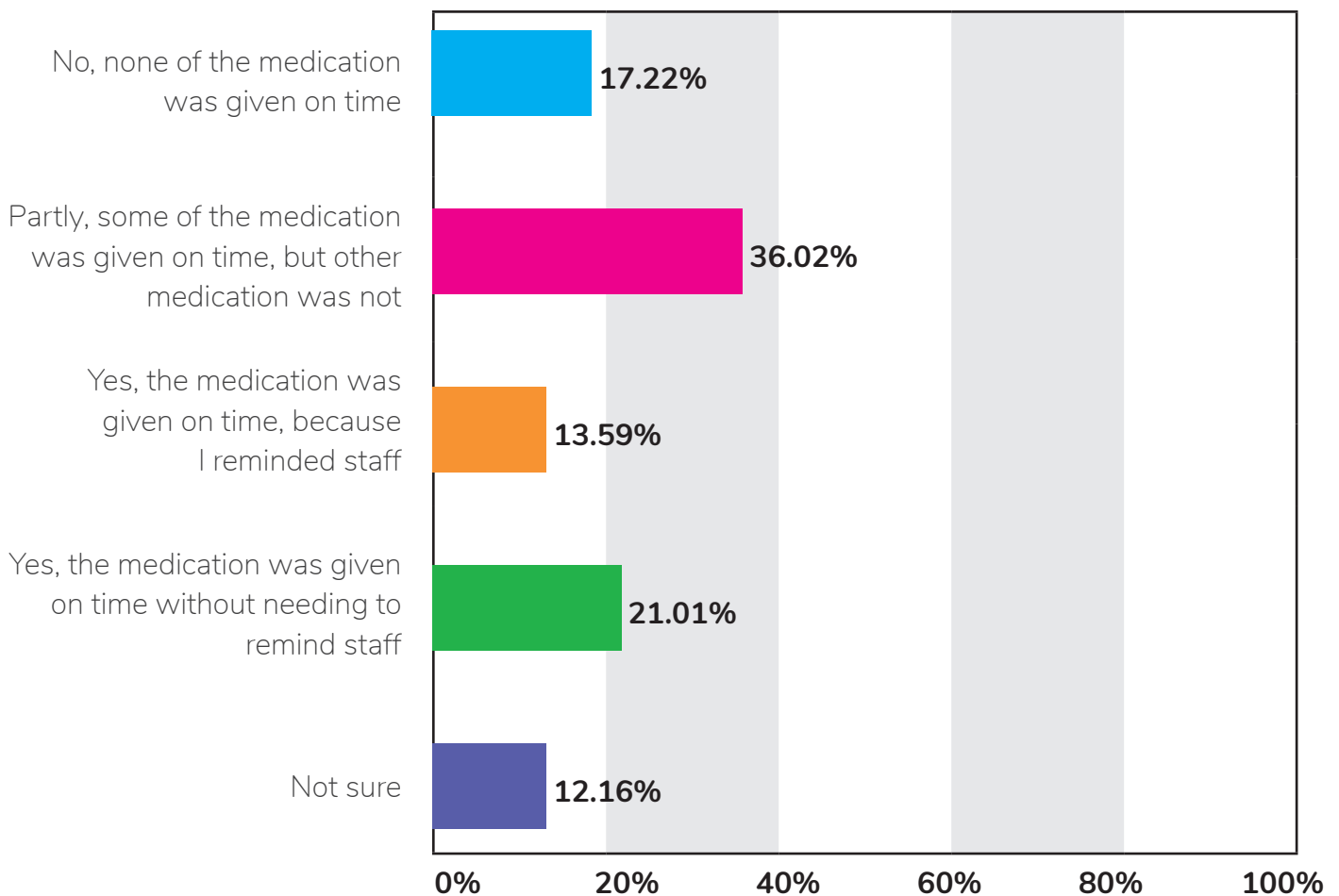
4. Did the hospital let patients take their own medication?



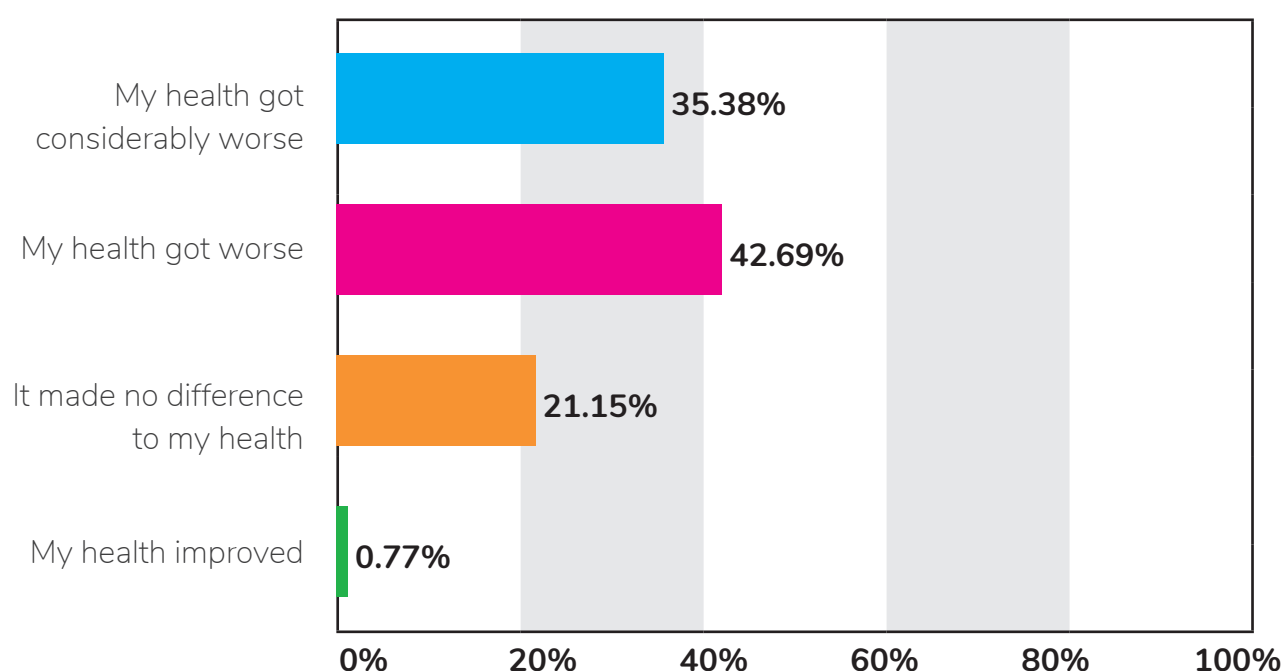
5. Did the hospital let carers stay outside visiting hours to help with medication?



6. During the most recent visit did you – or the person you care for – always get medication on time?



7. If your medication was not given on time, how did it affect you?



Appendix 3: Freedom of information request

We sent a freedom of information request to every UK hospital that supports people with Parkinson's, asking for information about various aspects of medication management. We made the request in April 2019. We received 112 responses from the 164 freedom of information requests we sent.

Raw data available on request for responses without answer summaries.

Training and staff awareness

Q1. What training is provided/sourced by the board to raise awareness among staff (in particular ward-based staff) about the needs of inpatients with Parkinson's, particularly around timing of medication?

Q2. How many a) staff overall and b) ward-based staff have undertaken such training during 2017/2018 and 2018/2019 to date?

Alert system

Q1. Does the board have any kind of electronic (or other) alert system in place to flag to the Parkinson's service when a person with the condition is admitted to hospital in a) a planned way and b) as an emergency?

Responses: 112

Do have an alert system: 49

Do not have an alert system: 64

Q2. If the board does not have an alert system, how are the Parkinson's specialist service notified and subsequently involved in the care of a person admitted with Parkinson's (whether or not Parkinson's is the reason for admission)?

Self-administration of medication policies

Q1. Does the board have a policy around self-administration of medication? If a policy does not currently exist, are there any current plans to implement one?

Responses: 112

Do have a policy: 82

Do not have a policy: 29

Q2. If a self-administration policy is not implemented, why is this the case?

Q3. If a self-administration policy is in place, what systems and protocols are in place to a) ensure full and effective implementation and b) monitor its implementation?

Responses: 83

Audit of policy use: 35

No audit of policy use: 48

Carers

Q1. Does the board have a policy that allows carers to visit the person with Parkinson's they care for outside visiting hours?

Q2. What training do ward staff receive to ensure they fully understand how a carer can support an inpatient with things such as mobilising and their medication regime etc?

Q3. What systems and protocols are in place for ward staff to work with carers supporting the person with Parkinson's in hospital to ensure flexibility when the need arises?

Practical resources

Q1. Is the board aware of the practical resources available from Parkinson's UK to support Parkinson's patients getting their medication on time (eg laminate bedside clocks, washbags) and how to access these resources?

Responses: 112

Aware of Parkinson's UK resources: 95

Unaware of Parkinson's UK resources: 17

Using Parkinson's UK resources: 77

Q2. Does the trust make use of these practical resources?

Patient safety incidents

Q1. Are incidents of a) missed Parkinson's medication doses and b) delays in the administration of doses of Parkinson's medication reported as patient safety incidents through local reporting arrangements?

Responses: 112

Record patient safety incidents: 93

Do not record patient safety incidents: 19

Do not record patient safety incidents by condition: 46

Q2. How many Parkinson's patient safety incidents relating to medication were recorded in your board in the last reporting period?

Q3. How many complaints has the trust received about missed or delayed administration of Parkinson's medication in a) 2017/2018 and b) 2018/2019 to date?

**Your mum, son or neighbour. Anyone can get Parkinson's,
young or old. Every hour, two more people are diagnosed.**

Parkinson's is what happens when the brain cells that make dopamine start to die. There are over 40 symptoms, from tremor and pain to anxiety. Some are treatable, but the drugs can have serious side effects. It gets worse over time and there's no cure. Yet.

But we know we're close to major breakthroughs. By funding the right research into the most promising treatments, we get closer to a cure every day.

Until then, we're here for everyone affected by Parkinson's. Fighting for fair treatment and better services. Making everyone see its real impact.

People with Parkinson's, scientists and supporters, fundraisers and families, carers and clinicians, all working side by side. Impatient for change, we're taking a stand, speaking out, chipping in, and playing our part.

**We are Parkinson's UK. Powered by people.
Funded by you. Together we'll find a cure.**

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
Monday to Friday 9am–7pm, Saturday 10am–2pm
(interpreting available)
NGT Relay **18001 0808 800 0303**
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk

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