Parkinson's UK Scotland

Time critical medication summit

Report and next steps

“Now is the time for government and healthcare services to produce a win on their own turf, for the benefit of every patient who relies on getting crucial medication on time, every time.”

Roddy Forsyth

Foreword

I was delighted to chair Parkinson's UK Scotland's time critical medication summit to explore what needs to change so that patients get their medicines on time, every time in hospital.

I was recently admitted to hospital for a hip replacement operation. During my stay, I was in the lucky position of being physically and mentally well enough to manage my own medication. I was also in a ward with healthcare professionals who understood why it was important for me to take my medicines on time. You might think that this would be a standard experience for patients across Scotland. But sadly this isn't the case. Far too often people with Parkinson's or other conditions that require time critical medication don't get these vital medicines on time.

Parkinson's medication is part of a group of medicines that are time critical. It can be dangerous if medicine is taken early, late or missed. NICE best practice guidance states that levodopa-based medicines must be given within 30 minutes of their prescribed time. So I was surprised to learn that only 42 percent of patients with Parkinson's reported getting their time critical medication on time while in hospital. A serious and dangerous shortfall when dealing with time critical medication.

I found the time critical medication summit both alarming and encouraging. Alarming in that there is significantly incomplete use of best practice amongst NHS boards. And encouraging in that decision-makers from the NHS, government and third sector recognised the urgency and listened with empathy to the experiences of people with Parkinson's and their loved ones.

Discussions highlighted challenges from under-staffing in hospital wards and increasingly complex care needs. This makes it all the more important for the NHS to use assistive technology and learn from examples of best practice. For example, during the summit, Parkinson's nurse Nick Bryden shared how NHS Ayrshire and Arran are using their digital prescribing system to improve how time critical medicines are given with real-time monitoring and data. This work shows that change is possible.

In the business I came from, the reporting of action in major sporting events, everything was time critical. But not a matter of life and death, despite Bill Shankly's famous quote, unlike the rigorous and time-specific administration of crucial drugs.

Now is the time for government and healthcare services to produce a win on their own turf, to the benefit of every patient who relies on getting crucial medicines on time, every time.

We are grateful to everyone who shared their insight and experience to inform this report, and look forward to continuing to work together to achieve the change that is needed.

Roddy Forsyth
Summit Chair and former Sports Journalist

What are time critical medicines and why do they matter?

Time critical medicines are an important patient safety issue.

Many medicines can be delayed or missed without causing major harm. But for people with certain conditions including Parkinson's, epilepsy and diabetes medicines are time critical.

When people don't get their Parkinson's medication within 30 minutes of their prescribed time, they can become extremely unwell. Yet fewer than half of all Parkinson's medicines are administered on time in Scotland's hospitals.

And that can mean terrible experiences for people and their families, additional workloads for frontline ward staff, and longer stays in hospital. Some people never recover.

“My husband lived with Parkinson's for 27 years. It was ok at the beginning, until he started having falls and spending a lot of time in hospital. He was in for a full year once. Every day was a fight.”

Linda Corbett

Learning from our Time Critical Medication Summit

Parkinson's UK Scotland held a cross-sector summit on Tuesday 26 November 2024, to share information and good practice about safe administration of time critical medicines in hospitals.

We brought together leaders from across government, healthcare, the third sector and members of the Parkinson's community.

During the event, delegates discussed:

- examples of good practice and potential solutions
- the barriers and challenges that need to be overcome to implement these solutions
- next steps and actions to drive forward improvement.

Following the summit we grouped and reflected on delegates' contributions. Through this process we identified the following key themes to guide future improvement activity. These themes are inter-connected and overlapping.

System-wide improvement

We heard from delegates that improvement requires a system-wide approach. This includes national commitments and action from government and NHS leadership, from health board management and within individual hospitals, services and wards. Delegates highlighted that time critical medicines risked getting lost amid competing pressures and priorities in the health service and needs to be a greater focus of national patient safety work.

Leadership and culture

Delegates told us it was important to foster leadership and culture at all levels to support improvement. Delegates said that this leadership needed to be top down and bottom-up. They told us hospital staff play a crucial role in improving how time critical medicines are administered. But they felt these staff needed to be supported by national and regional commitment so that they had the training, resources and time to make improvements.

Education and training

Education and training was highlighted both as a solution but also a barrier. Delegates felt it was vital all healthcare staff have access to training and time to complete it. While they acknowledged that there are already resources available (for example Parkinson's UK has a hub of resources for healthcare professionals) more work was needed to make sure everyone involved in time critical medicines knows about these resources and understands why this training is important for their role.

Digital tools and data

We heard that digital tools and data were an important tool to reduce late and missed doses of time critical medicines. During the summit, we heard about good practice in NHS Ayrshire and Arran where staff are using the HEPMA digital prescribing system to get real-time data and alert ward staff when time critical medicines are due. Delegates were enthusiastic about how digital tools and data could support improvement. But they raised a number of barriers, including how different IT systems work together, the time and expertise required to programme these systems to provide reports and alerts, and the need to overcome fear of what the data might show.

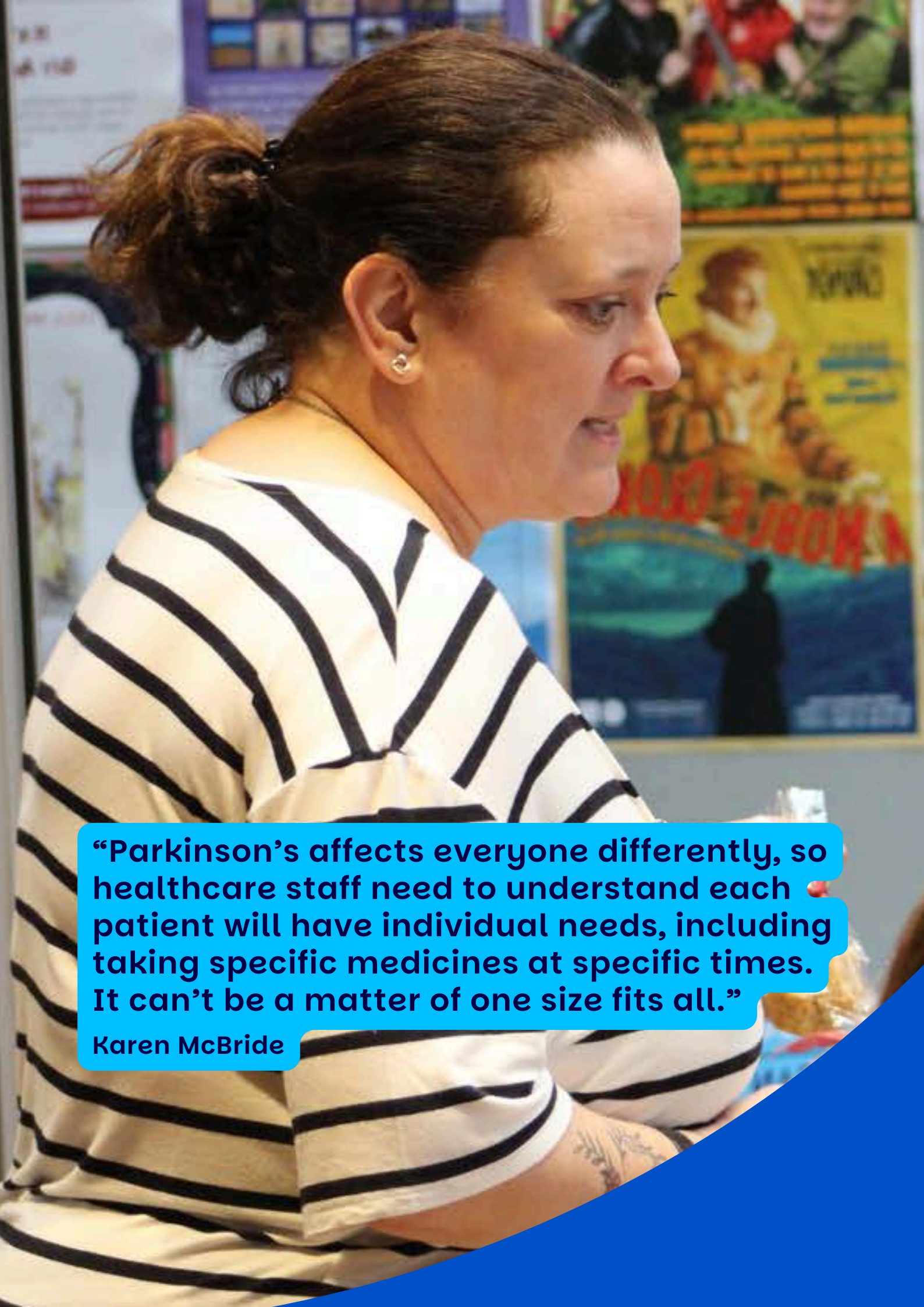
Ways of working

Delegates highlighted how existing ways of working could make it difficult to administer medicines on time. Some of the barriers included workforce pressures and short-staffing, ward routines where medicines take place at set times, and unavailability of Parkinson's medicines in hospital pharmacies. Delegates told us there needed to be greater awareness among healthcare staff of the consequences of missed or late doses for patients, that Parkinson's patients should be identified as soon as possible on admission, and that ward routines and policies needed to be flexible so patients could get their medicines when they need them.

Self administration and patient (and carer) empowerment

We heard that it was important for healthcare staff to respect patients' and carers' expertise in managing their condition and listen to them. Delegates highlighted the importance of supporting patients who can self-medicate to safely do so and encouraging patients to keep up-to-date lists of their medicines and when they take them. Delegates also highlighted that even where patients are unable to self-medicate, healthcare workers should still speak to them and loved ones who care for them to understand their individual needs and concerns and agree a plan to make sure they get their medicines on time.

A detailed summary of comments from delegates is included in the Appendix.



“Parkinson’s affects everyone differently, so healthcare staff need to understand each patient will have individual needs, including taking specific medicines at specific times. It can’t be a matter of one size fits all.”

Karen McBride

Next steps

The summit highlighted that there are real, actionable solutions to drive forward improvement so that more inpatients get their medication on time.

While there is no silver bullet, there are clear opportunities to galvanise leadership nationally and locally, to harness the power of digital tools and data, and embed training and awareness across the workforce to deliver safer care.

These next steps are rooted in the insights we heard during our summit and are informed by Parkinson's UK's long-running activity working with people with Parkinson's and healthcare professionals, to improve how time critical medicines are administered.

Leadership and system-wide improvement

We need a Scotland-wide medicine quality improvement (QI) programme, as a key element of patient safety activity in Scotland.

This programme should support coordinated action across long-term conditions most affected by time critical medicines. It should provide a framework for partnership working between NHS Healthcare Improvement Scotland, NHS Health Education Scotland and NHS boards, and involve people and families with lived experience. It should use data to measure progress and identify challenges. NHS England is developing QI in this area, and there are existing QI projects that could be spread.

Data and digital tools

NHS boards should use HEPMA systems to implement a Scotland-wide framework for collecting and reporting data on the administration of time critical medicines in hospitals. NHS Boards should use this data to drive improvement and develop real-time alert systems. Read more about NHS Ayrshire and Arran's work.

The Parkinson's UK model of the economic impact of time critical medicines will be ready in Spring 2025. Government and NHS boards should consider using this interactive tool to assess the financial costs of poor Parkinson's medication administration within their services.

The next UK Parkinson's Audit will include an audit of inpatient medicines administration for the first time. The audit is not onerous. The Scottish Government should encourage every NHS Board to take part in the 2025 and future UK Parkinson's Audits. Find out more about the UK Parkinson's Audit.

Education and awareness

A national improvement programme should be underpinned by a national education programme, delivered through NHS Education for Scotland (NES). NES should consider how to

use and build on existing resources and expertise from organisations like Parkinson's UK, as well as engaging with patients and carers to learn from their experiences and perspectives on what works.

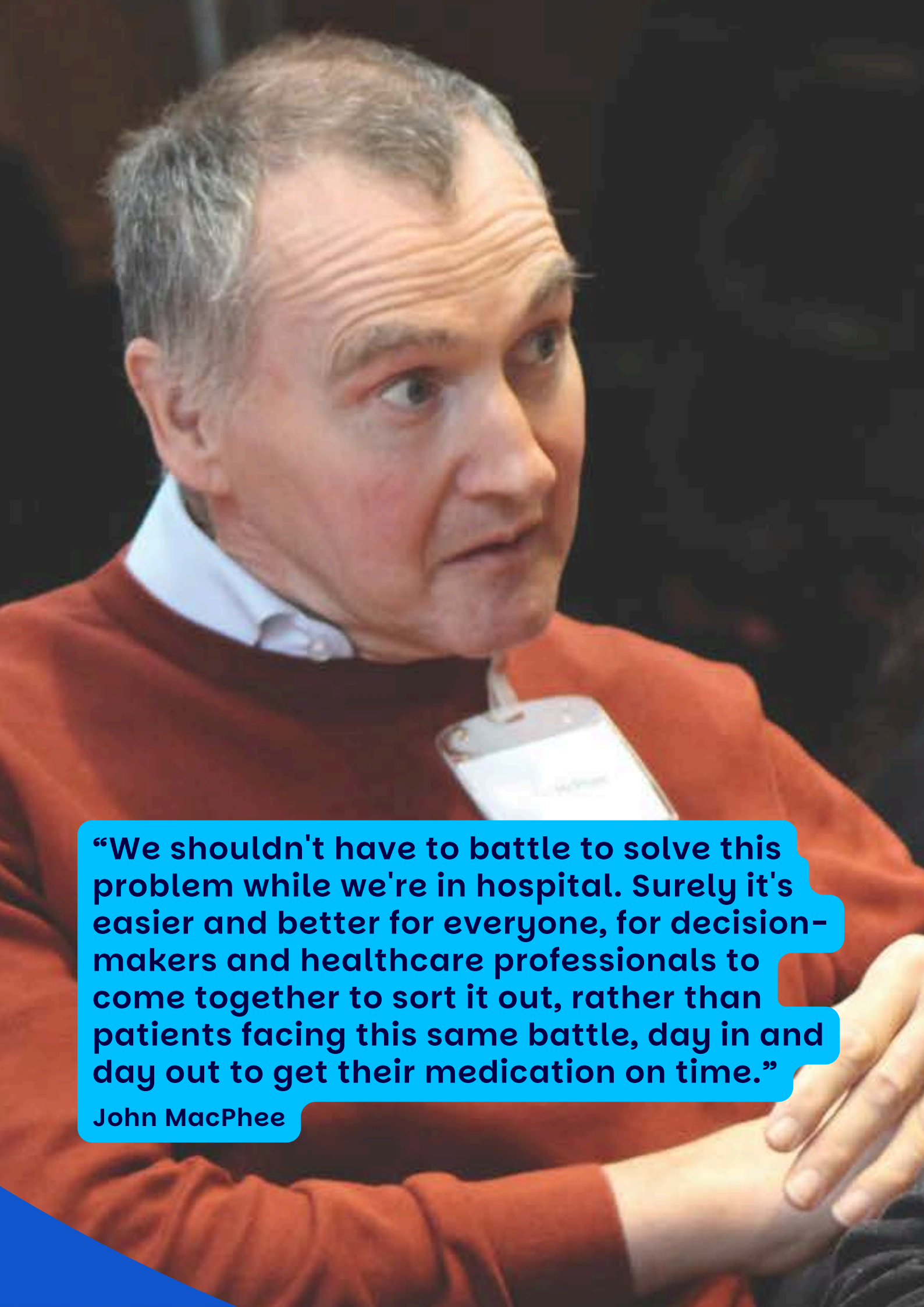
The forthcoming Scottish Government polypharmacy guidance update will highlight the importance of time critical medicines for Parkinson's and other conditions and inform healthcare professionals on how they can ensure these medicines are administered on time and safely in hospital settings.

Workforce pressures and processes

Initiatives to improve time critical medicine administration in hospitals should identify where existing workforce pressures and processes are creating barriers to improvement and support practical solutions, including those outlined in the Parkinson's UK 10 recommendations for your hospital in Scotland resource. Parkinson's UK is currently seeking pledges of support from NHS Boards for implementing the 10 recommendations locally. Read our 10 recommendations for your hospital resource.

Self-administration and empowering people

All NHS Boards should have up to date self-administration policies in place so that inpatients who can take their medication themselves are empowered to do so at the times that are right for them.


“We shouldn't have to battle to solve this problem while we're in hospital. Surely it's easier and better for everyone, for decision-makers and healthcare professionals to come together to sort it out, rather than patients facing this same battle, day in and day out to get their medication on time.”
John MacPhee

Appendices

Solutions and good practice

Delegates discussed existing and potential solutions and good practice. Six themes emerged:

Theme
System-wide improvement which encompasses national (government / NHS leadership), regional (health board) and local (individual hospital, ward, service) action. This needs to cut across departments, professional groups and services.
Summary of comments
Importance of a whole-system approach. Opportunities for a Quality Improvement (QI) approach at national and local level, for example, the current Royal College of Emergency Medicine Quality Improvement programme on time critical medications in Type 1 A&E departments across the UK. NHS Healthcare Improvement Scotland (HIS) and NHS Education Scotland (NES) are key partners for delivering this. No 'silver bullet', actions across education and systems, and partnership working, are all needed. Time critical medicines need to be recognised as a patient safety issue. Important to work in collaboration across conditions where time critical medicines are an issue (for example Parkinson's, epilepsy, diabetes). Up-stream solutions, bolstering community services and support to reduce hospitalisations in the first place.

Theme
Leadership and culture both at ward / service / hospital level and senior management / national leadership to commit to action and drive it forward.
Summary of comments
Recognise and encourage leadership within the healthcare workforce at all levels. Not just those in 'leadership roles'.

Potential role for Parkinson's nurses as champions / advocates.

Empower and support ward staff by providing time, resources and authority for them to lead change.

Provide top-down leadership as well as grassroots leadership. There needs to be commitment at highest levels to prioritise, support and promote improvement activity. This should include engagement from patient safety and clinical governance, practice education and quality improvement teams.

Don't be afraid of the data. A poor baseline just better demonstrates the need for improvement.

Avoid a blame culture and enable free and open discussion.

"It's not just about training. It's about buy-in, 'hearts and minds'".

Theme
Education and training including how to improve take-up of existing resources, develop and improve resources, and foster a culture of learning.
Summary of comments
A need to review existing education and training options and resources identified. There may be limited knowledge of current resources on time critical medicines. How can we make the existing resources more accessible and increase take-up? Poster with QR code in healthcare settings (these are available but not widely used currently). Are existing education materials available on TURAS and any other learning platforms accessed by relevant healthcare staff? Importance of embedding the voices and experiences of inpatients and their families into training to highlight impact. Targeted training for professionals integral to time critical medicines administration, for example, ward nurses. Indirect education is also important. Encourage questioning and learning on job, willingness to try things and learn through change. Include tools to support improvement within guidance. While the summit focused on hospital settings, education and training resources should be available to healthcare staff in all settings where people rely on time critical medicines, including care homes.

Theme
Digital tools such as Hospital Electronic Prescribing and Medicines Administration (HEPMA) and gathering and using **data** to drive improvement.
Summary of comments
Consistent auditing of delayed and missed medication would provide reliable data to drive and inform improvement. Importance of linking HEPMA with other systems. Developing a national agreed admission process and electronic prescribing record. NHS Ayrshire and Arran model could help reduce development time because learnings can be applied to other health boards. Need to know who is responsible for driving project, auditing and interpreting data on ongoing basis. HEPMA is used across health boards but there are variations in implementation. How can IT systems prompt staff to give medication on time (like the NHS Ayrshire and Arran tulip system)? Develop consistent systems and structures for coding time critical medication on digital records and systems. Parkinson's UK has commissioned a health economics model for time critical medicines for publication in spring 2025. This should provide further data on the impact of this issue and drive action.

Theme
Ways of working and processes. Different ways of working and processes which could be reviewed and improved.
Summary of comments
Need to sort out emergency medicines access so time critical medication are always available. Some departments have a 24-hour delay to access medications. Important to identify inpatients with Parkinson's and other conditions that require time critical medicines.

Right care, right place. It's important to deliver care in most appropriate ward or service, for example, a specialist ward.

Parkinson's nurses supporting general staff with advice as needed.

Elective care settings could offer an opportunity to test improvement activity in a more controlled setting (compared to unscheduled care) for example, using pre-assessment to identify time critical medicine requirements.

Theme
Self-administration and empowering people and families. Empowering people and their families through information, sharing and listening, as well as implementing self-administration policies so inpatients who can self-administer are supported to do so safely.
Summary of comments
Patients and carers should be encouraged to bring medicines with them when going to hospital, not assuming medicines will be available when there. Healthcare professionals working with patients and families should emphasise the importance of having an up-to-date list of their medications and prescribed times that they can share with hospital staff. Self-administration policies should be in place (currently only half of health boards have one and there is variation in implementation). Where safe to do so, inpatients should be supported and empowered to self-administer their time critical medicines. Communication between healthcare professionals, inpatients and carers is important. Important for professionals to recognise the expertise and experience that people and their families have in managing their conditions. Education is also important for people and families so that they know what to expect when they go into hospital and feel empowered to advocate for their medication. People and their families need to understand the importance of having an up-to-date list of their medicines and the prescribed times. Healthcare staff also need to understand this might not always happen or be possible. People with Parkinson's should be copied into all communication with specialists and nurses, to equip them and families with information to hand over when they are admitted.

Barriers and challenges

Delegates discussed the barriers and challenges to achieving change.

Note that many barriers and challenges cut across multiple themes.

Theme
System-wide improvement which encompasses national (government / NHS leadership), regional (health board) and local (individual hospital, ward, service) action. This needs to cut across departments, professional groups and services.
Summary of comments
Existing improvement activity has been in isolated pockets of good practice, not system-wide. Lack of buy-in at government level and competing priorities (need leadership and commitment from the top to drive change). Lack of recognition of time critical medication within current patient safety programmes. Risk of time critical medication getting lost amid other government-mandated priorities and targets. While discussion was focused on hospitals, it's important that the care home sector also has access to education on time critical medicines.

Theme
Leadership and culture both at ward / service / hospital level and senior management / national leadership to commit to action and drive it forward.
Summary of comments
There are significant pressures facing healthcare workers and settings which could be barriers to improvement. But delegates questioned whether these barriers were becoming excuses for inaction or lack of progress. Lack of time to engage with patients, co-design solutions, develop IT infrastructure, foster leadership.

Culture on wards could be a barrier.

Theme
Education and training. Including how to improve take-up of existing resources, develop and improve resources, and foster a culture of learning.
Summary of comments
Inpatient population has increasingly complex needs. Limited permanent staff on wards and an over-reliance on bank / agency staff means there is a lack of buy-in to improve care and undermines sustained improvement. When everything is urgent nothing is urgent. Healthcare staff need to understand how time critical medicines vary from general guidance and the consequences of later or missed doses. For most medicines the recommendation is to give doses within 60 minutes before or after the specified time in contrast to the 30 minute window for Parkinson's medicines.

Theme
Digital tools such as Hospital Electronic Prescribing and Medicines Administration (HEPMA) and gathering and using **data** to drive improvement.
Summary of comments
Technology is important but it's not a solution in isolation. Interoperability of systems. IT systems like HEPMA and patient record system don't interlink / communicate. Challenges around inputting the right medications into the HEPMA system. Data fear, need to overcome fear of data, especially if data looks bad. Challenges around coding and programming systems to do what we want, may not have been part of previous commissioning process.

Needs support and buy-in from IT and suppliers.

Need to consider low-tech solutions, especially if barriers to utilising and updating systems becomes a delay to improvement. Don't wait for the tech.

Developing alert systems is a step beyond gathering and monitoring data.

Patient involvement in developing digital tools and systems.

Theme
Ways of working and processes. Different ways of working and processes which could be reviewed and improved.
Summary of comments
Identification of people with Parkinson's and others on time critical medicines is important. Unintended harms and costs as a result of medication delays and missed doses. These include the impact on the wellbeing of patients and carers, the increased care and recovery needs of patients, and increased staffing and ward resources. Short staffing feeds into lack of awareness and implementation of self-administration policies. Lack of awareness of consequences for delayed or missed doses and why it matters for patients. Time critical medicines schedules don't match general ward workflows and routines. Patients aren't always told to bring their medicines with them to hospital and sometimes are discouraged from doing so. Unavailability of medicines at hospital pharmacies can lead to delays.

Theme
Self-administration and empowering people and families. Empowering people and their families through information, sharing and listening, as well as implementing self-administration policies so inpatients who can self-administer are supported to do so safely.

Summary of comments
Relying on patient voice advocacy can be difficult. People with Parkinson's may not be able to speak for themselves, there are high rates of communication issues, delirium and dementia.

Who took part

Roddy Forsyth
Summit chair and former Scottish football correspondent for BBC Radio Sport and the Telegraph Group, now retired due to Parkinson's

Professor Alison Strath
Chief Pharmaceutical Officer, Scottish Government

Dr Alpana Mair
Head of Effective Prescribing and Therapeutics, Scottish Government

Annalena Winslow
Head of Safety, Openness and Learning, Scottish Government

Craig Kennedy
Clinical Priorities Team, Scottish Government

Professor Graham Ellis
Deputy Chief Medical Officer, Scottish Government

Kathryn Brechin
Professional Adviser to the Chief Nursing Officer Directorate, Scottish Government

Richard Brewster
Clinical Priorities Team, Scottish Government

Dr Sam Patel
Clinical eHealth Lead, NHS Education Scotland and Consultant Physician, NHS Lanarkshire

Dr Susan Duncan
Board Member, Epilepsy Scotland

Dr Bob Caslake
Consultant in Medicine for Older People and British Geriatrics Society Scotland Chair

Dr Conor Maguire
Consultant in Medicine for Older People, Royal College of Physicians Edinburgh Vice Chair

Fiona McIntyre
Policy and Practice Lead, Royal Pharmaceutical Society Scotland

Jane Raitt
Representative of Healthcare Professionals with Parkinson’s Network

Lorna Gilles
Parkinson's Specialist Nurse

Nick Bryden
Parkinson's Specialist Nurse and Chair of the Association of Scottish Parkinson's Nurses

Dr Anne-Louise Cunnington
Consultant in Medicine for Older People and UK Parkinson's Audit Lead

Karen McBride
Person with Parkinson's

John MacPhee
Person with Parkinson's

Linda Corbett
Family member

Laura McClung
Family member

Marian Reilly
Family member

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James Jopling
Scotland Director

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Programme Manager, Time Critical Medication

Mary Ellmers
Service Improvement Manager

Sam Matson
Service Improvement Adviser

Tanith Muller
Parliamentary and Campaigns Manager

Mairi Gordon
Campaigns and Policy Officer

Iain Stephen Morrison
Media and Communications Officer

Karen’s story

Hear about Karen's experience in hospital and how this impacted her health afterwards.

Scan the code to view the video or visit our website for more patient stories and information on time critical medication.