

PARKINSON'S<sup>UK</sup>  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

# Get It On Time

Engaging Networks Conference  
21.05.20

# The problems

Timely medication is so important!

- Manage symptoms
- One dose can be all it takes
- Loss of independence
- Irreparable worsening of condition





# Our evidence

- 50% of people not getting medication on time (2017 Audit)
- 69% not getting medication on time (2018 Your Life Your Services)
- In 2017, NICE recognised the importance of Parkinson's drugs as an area for quality improvement
- £10m in excess bed days in England

# Theory of change



# The causes of the problem

Knowledge of  
Parkinson's

Lack of established  
processes

Barriers to taking  
medication by  
yourself

Technology

Lockable cupboards

Pharmacist

Capacity

Record keeping

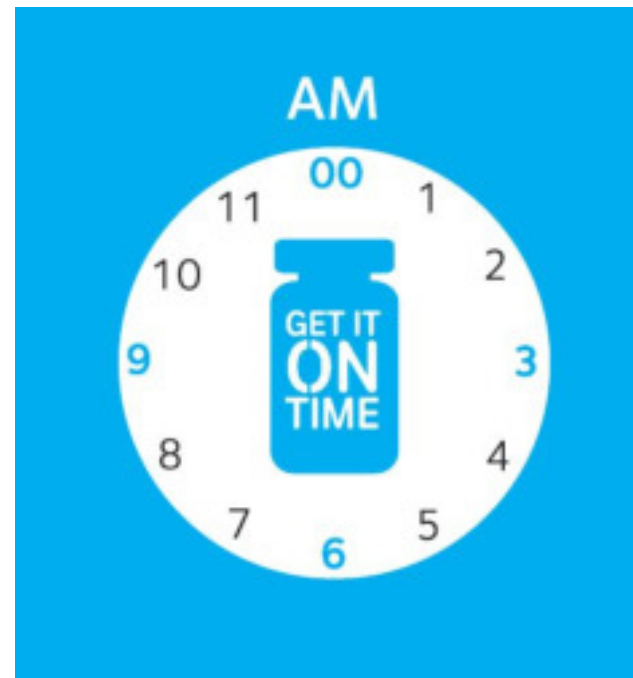
# How can we fix it?

Headline focus on:

- Mandatory learning
- Universal coverage of self-administration policies

National influencing on:

- Digital systems
- Inspections framework



# Video



# Campaign flow

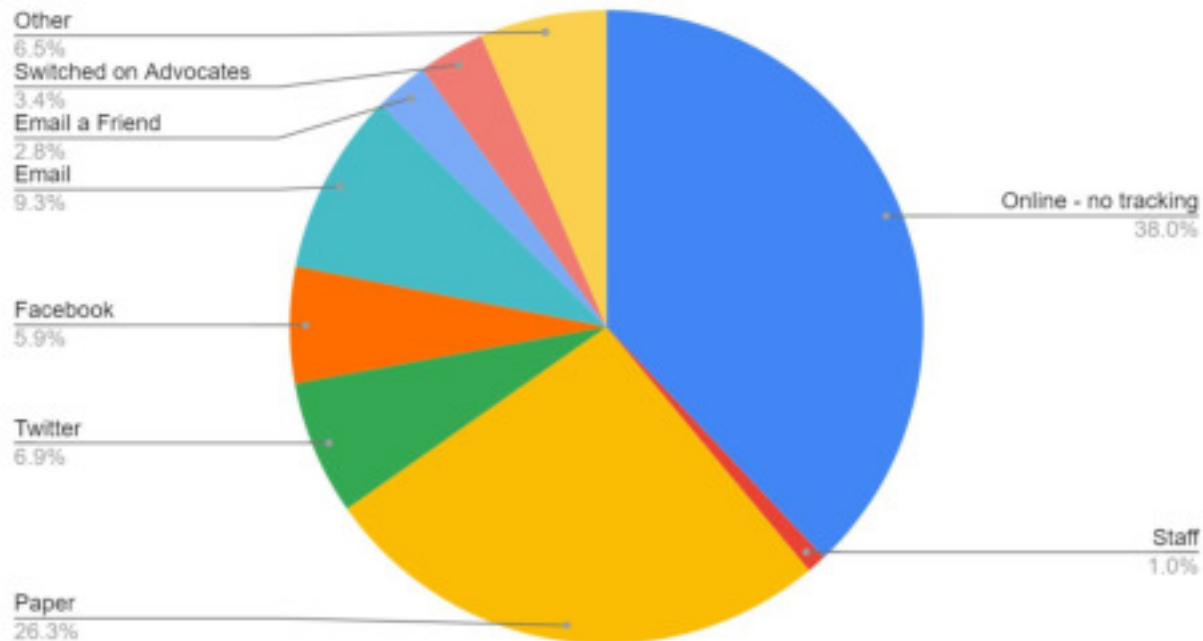




# Petition

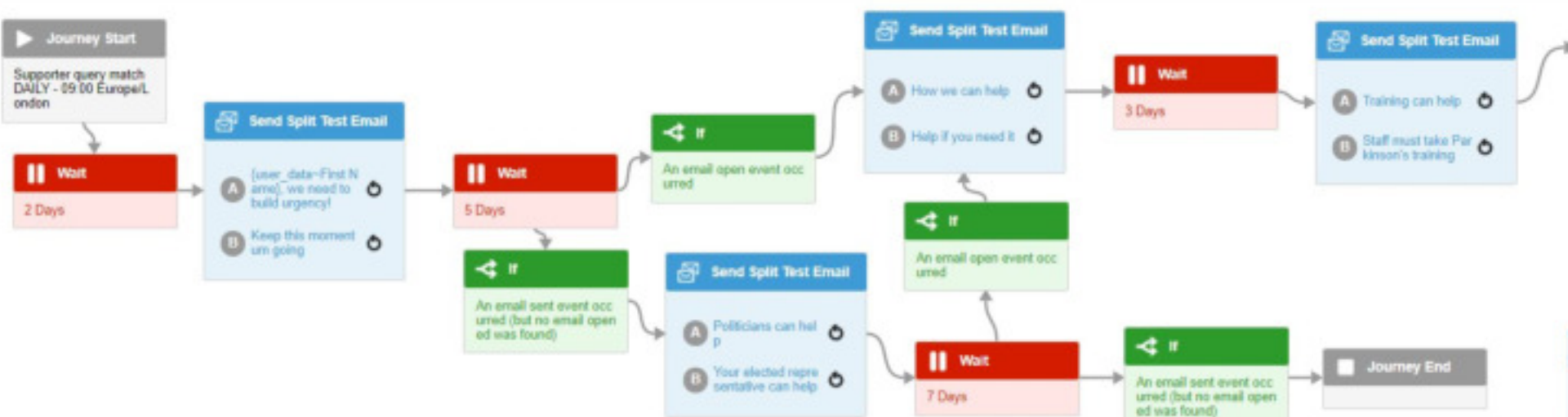
THANK YOU ALL FOR SIGNING OUR PETITION!

18,549

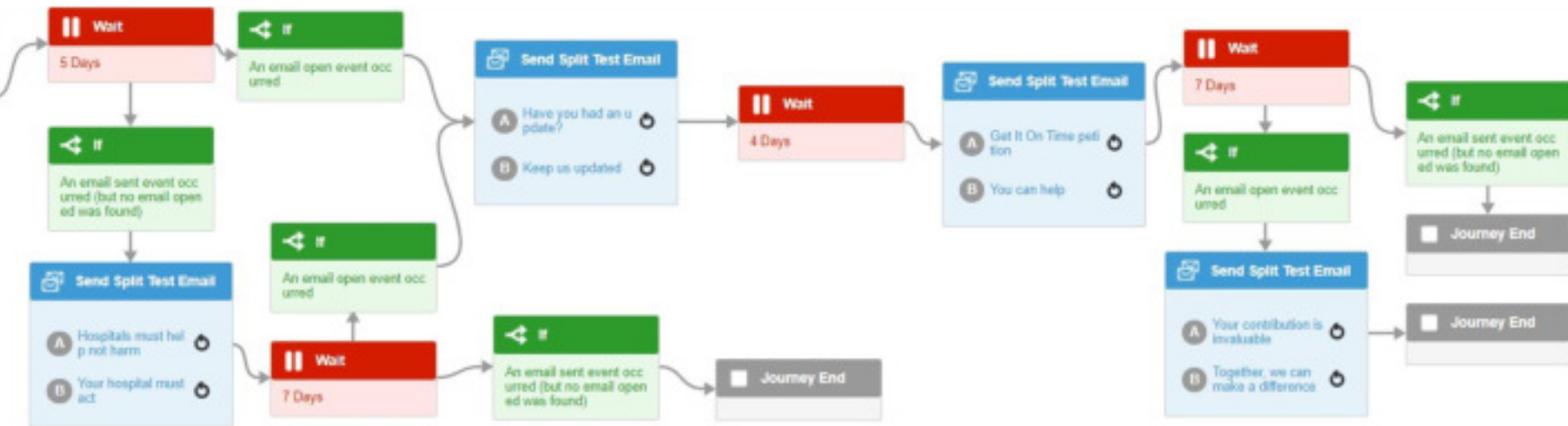


Objectives		
<p>Everyone with Parkinson's receives their medication on time every time when in hospital.</p> <p>There is mandatory training on Parkinson's in every hospital.</p>		
Key result	Actual	
<b>Build understanding and indignation</b> among our audiences over the issue of people with Parkinson's not getting their medication on time.	Engaging and relevant key messages used consistently across comms to varied audiences on diverse channels including paid, owned and earned channels. Strong video creative mobilised a wide audience.	✓
<b>Influence decision-makers</b> via the report to ensure that <b>10</b> new hospitals agree to hold mandatory training on Parkinson's and <b>10</b> new hospitals have up to date self admin policies	Parliamentary drop in event held with <b>20 MPs</b> . <b>1,093 emails sent directly to hospitals</b> .  Ongoing: training and self-admin policy take up from hospitals	<b>9 Policy changes</b> <b>17 in pipeline</b>
<b>Galvanise 10,000 people to sign a petition</b> to commit all hospital staff to take simple training about Parkinson's once a year	Signatures: <b>18,500+</b>	↑ 85%
<b>33%</b> of our core audience who sign the petition go on to <b>become committed Get It On Time campaigners</b>	Email journey opt in Core: <b>36%* (Online only - 41%)</b> (SOAs: <b>39%</b> )  <b>Almost 2,000</b> sent to target decision makers	↑ 39%
Ensure people have <b>access to the information and support</b> we can provide around the issue	Relevant information and support shared across comms	✓

# Email Journey



# Email Journey (2)



- 1) Screen out inactive early
- 2) Only offer biggest asks to most active

# New template

Commissioned new template

Previous petition:

22% PC and 5% Phone

New:

23% PC and 50% Phone

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
**JOIN US.**

**GET IT ON  
TIME**

People constantly tell us about the impact of not getting medication on time in hospital – stress, anxiety, immobility, severe tremors. Nearly two-thirds of people living with Parkinson's didn't consistently get their medication on time in hospital.

Unfortunately, the majority of hospitals just don't comprehend the urgency of getting medication on time, **every time.**

First Name

Last Name

Postcode

Email Address

We'd also love to stay in touch by email with our latest news on everything we're doing to lead the fight against Parkinson's including fundraising, campaigning, services, research and volunteering.

☐ Yes, send me emails  
☐ No

**Sign the petition**

18,549

**TARGET: 20,000**

**THANK YOU BENALI**

We can't wait another minute – we know people with Parkinson's need to Get It On Time.

Thank you for joining our call for mandatory training on Parkinson's in hospitals.

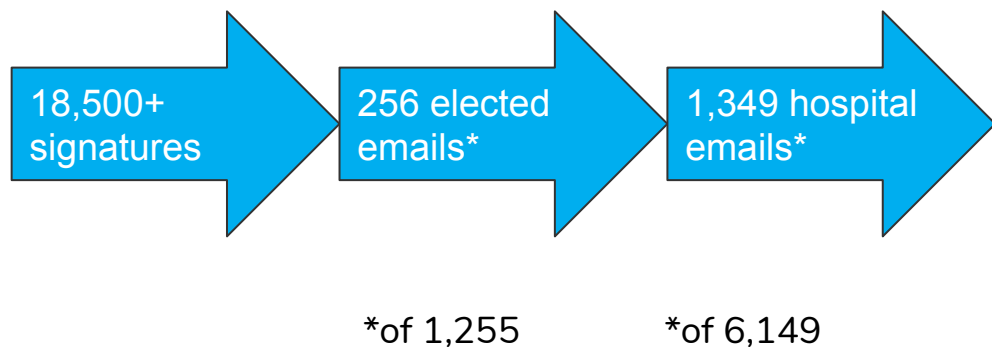
**Together, we will change this.**

 Share on Facebook

 Share on Twitter

 Email a friend

# Policy and Campaigns



## Opt ins

18,549 signatures

3,503 no emails

**Opt in:** 6,657  
(SOAs: 245)

35.8% (41%)

## Conversions

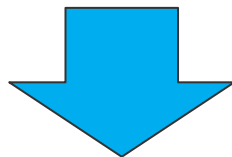
43,922 page views

14,973 participations

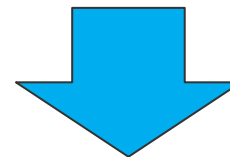
**34%**  
(SOAs: 30.5%)

Mobile: 50%  
PC: 23%

# FOI data



**Offer training**



**Develop policy**

# Reference data and redirects

Welsh AM				Scottish MSP				English MP				Northern Irish MP			
Match to a local hospital															
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English Hospital Trust (no mental health trusts)								Scottish, Welsh or Northern Irish Health Board							
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# Trusts

Redirect by country

Suppress non-acute trusts

Reference data

## Get It On Time

{contact\_data-salutation}

It is vital that people with Parkinson's in hospital get their medication on time, every time. Late or missed medication can have serious consequences on a person with Parkinson's health. That's why Parkinson's UK is launching their Get It On Time campaign - with a series of recommendations for hospital trusts and health boards.

When people with Parkinson's don't get their medication on time their symptoms can get out of control quickly, causing distress for everyone involved. Sometimes the deterioration they experience can be irreversible, leaving people permanently unable to walk or talk.

They can also end up needing to stay in hospital longer if their medication is not given on time. We know this costs the NHS money, with each excess bed day in a hospital costs a trust or health board an average of £345. Latest data shows that people with Parkinson's face 28,860 excess bed days in hospital every year in England alone - this costs the NHS £10m a year.

Yet the majority of people with Parkinson's who go into hospital do not get their medication on time. A Parkinson's UK's survey found that 61% of people living with Parkinson's do not always receive their medication on time when staying in hospital. {reference\_data-778-column1}

{reference\_data-778-column2}

Parkinson's UK have also produced a [Medicines Optimisation Consensus Statement](#). The document is a set of principles which professionals agree is good practice when managing the medication of people with Parkinson's. We believe this resource can be a starting point to help improve processes in local hospitals.

{reference\_data-778-column3} {reference\_data-778-column4} {reference\_data-778-column5} {reference\_data-778-column6}

I look forward to hearing from you

{user\_data-First Name} {user\_data-Last Name}

{user\_data-Postcode}

# MPs, MSPs & MSs

Redirect by country

Reference data

## Get It On Time

{contact\_data-valuation}

I am writing as your constituent in {contact\_data-organization} to ask you to read and act on [Parkinson's UK Get It On Time report](#). This report exposes the difficulty people with Parkinson's across the UK are experiencing getting their medication on time in hospitals.

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 or swallow. Some people may never recover and may permanently lose their ability to walk, talk or move.

Unfortunately, we regularly hear harrowing stories about people coming out more unwell from hospital than they went in. From two surveys with people with Parkinson's we found:

- 69% of people living with the condition did not always receive their medication on time when in hospital.
- 78% of those respondents told us their health got worse as a result of not receiving their medication on time.
- 47% were not given the option to administer their own medication, which could reduce help alleviate the number of missed or late doses.

Our research has discovered too many hospitals are not taking proactive steps to ensure people with Parkinson's get their medication on time. Through our Freedom of Information requests, we found that:

- Only 44% of trusts and health boards offer ward staff mandatory training on Parkinson's.
- 58% of hospitals do not record patient safety incidents for people with Parkinson's and therefore have no insight into the severity of issues.

We're therefore calling on the NHS to urgently act to ensure that every hospital trust and health board:

- implements mandatory training on Parkinson's for all hospital staff
- has 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.

In your area: {reference\_data-761-column1} {reference\_data-761-column2}

If you'd like to request any data for any other local trusts or to be given template letters to send to NHS decision makers please do email the Policy and campaigns team on [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk).

Nationally you can help by contacting the Department of Health and NHS England to encourage them to follow up and implement the recommendations from the [Get It On Time report](#).

Best wishes,

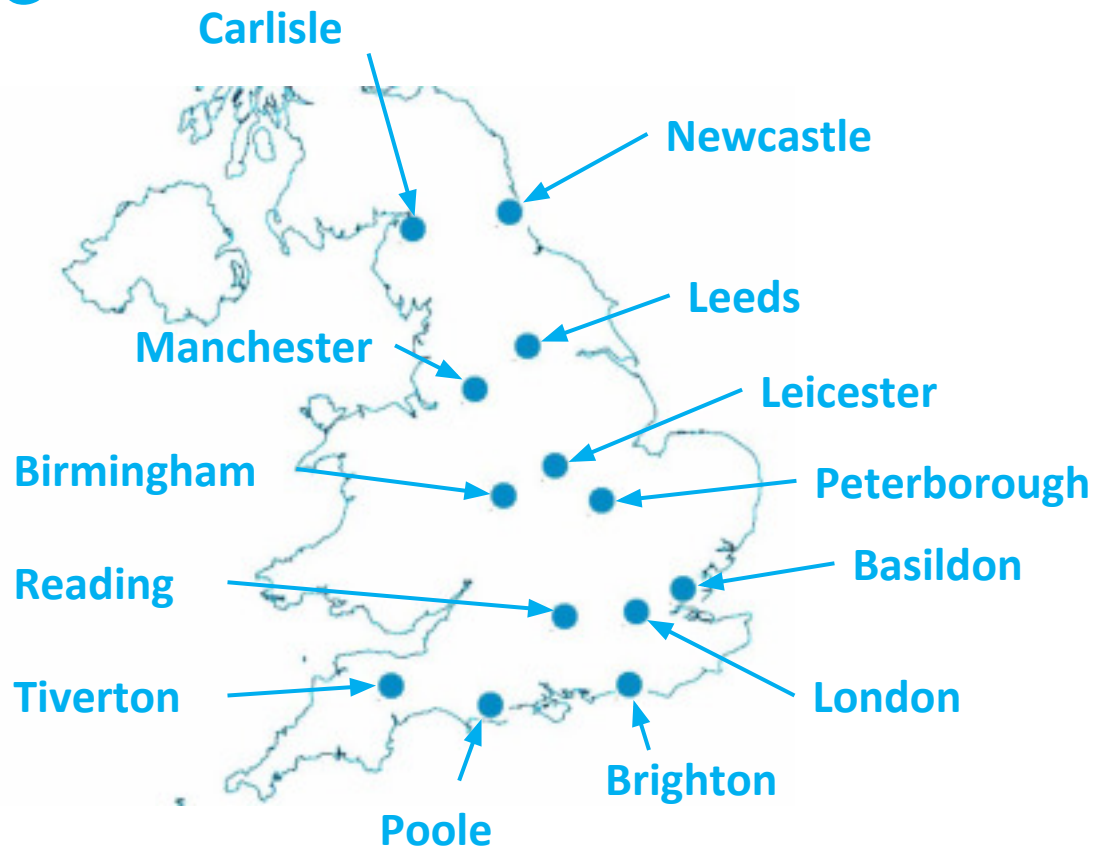
{user\_data-First Name} {user\_data-Last Name}  
{user\_data-Postcode}

# Volunteers

- 12 training days
- 70+ volunteers trained
- Regional presentations



# England wide



# Principles

- Decision maker meetings
- Collecting Petitions
- Story of self, data protection & collection ideas
- Concrete plans



# Email engagement

Two email journeys - **SOA** & **Core**

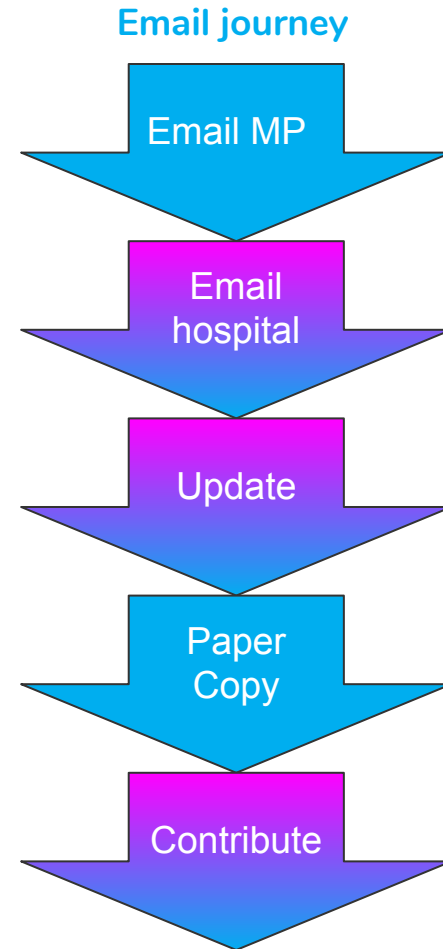
SOA:

Open rate - 58% Click to open rate - 33.8%

Core:

Open rate - 62.8% Click to open rate - 14.2%

£411 raised - 2632 emails



# Action from decision makers

Elected Representatives mobilised by online campaigners	<ul style="list-style-type: none"><li>• Letters to Caroline Dinenage</li><li>• Eluned Morgan AM</li><li>• Marcus Fysh MPs</li><li>• Swindon MPs</li><li>• Alex Chalk MP</li><li>• Llyr Gruffydd AM</li><li>• Debbie Abrahams MP</li></ul>
Elected Representatives mobilised by campaign volunteers	<ul style="list-style-type: none"><li>• Nottinghamshire MPs</li><li>• Parliamentary Reception</li></ul>
Hospitals influenced by online campaigners	<ul style="list-style-type: none"><li>• James Paget</li><li>• Ashford</li><li>• Morecambe Bay</li></ul>
Hospitals influenced by campaign volunteers	<ul style="list-style-type: none"><li>• Broomfield</li><li>• Peterborough</li><li>• Frimley</li><li>• Staffordshire</li></ul>

# Amplifying through social media

Average engagement on Facebook	6.3%	↑ (50% increase on benchmark)
Average reach on Facebook	44K	↑ (410% increase on benchmark)
Petition signatures from organic social	12.8% of total	





# Media and celebrity supporters




**Lorraine**  
 @LorraineBBC

Nearly two-thirds of people with Parkinson's don't get their meds on time in hospital. So ... help people with Parkinson's get their medication on time by signing the @ParkinsonsUK petition. It takes less than a minute: thank-you! #GetOnTime


 I had uncontrollable tremors, I couldn't do anything for myself, I literally couldn't function and was immobile." Paul

Sign our Get it On Time petition  
 People with Parkinson's need their medication on time every time.  
 @ParkinsonsUK


**Emma McCulloch**  
 @emma\_mcculloch

So important! Great to see #TheGinneman from @TheChosenUK backing this new campaign by @ParkinsonsUK @TeamParkinsons on @Lorraine @realLorraine this morning #getontime #Parkinsons #medication


**Parkinson's UK**  
 @ParkinsonsUK


 I had uncontrollable tremors, I couldn't do anything for myself, I literally couldn't function and was immobile." Paul


**Julie Kay OBE**  
 @JulieKayOBE

Nearly two-thirds of people with Parkinson's don't get their needs on time in hospital. You can help people with Parkinson's get their medication on time by signing the @ParkinsonsUK petition. It takes less than a minute to help them #GetOnTime


 I had uncontrollable tremors, I couldn't do anything for myself, I literally couldn't function and was immobile." Paul

Sign our Get it On Time petition  
 People with Parkinson's need their medication on time every time.  
 @ParkinsonsUK



## NursingStandard

View published

New draft

Moderate

Search...

NEWS

### Mandatory training needed to improve Parkinson's care, says charity

PARKINSON'S<sup>UK</sup>

# Mobilising new audiences

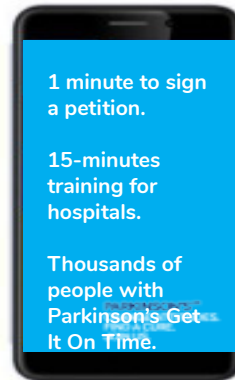
BUILD CONDITION UNDERSTANDING & EMPATHY  
DEEPEN ENGAGEMENT

TAKE ACTION

Brand  
campaign

Content Marketing

Get It On  
Time



# Mobilising new audiences

Paid social



Email acquisition

Petition

A screenshot of a mobile petition form. It has a dark blue header with the word 'Petition' in white. Below the header are four white input fields with blue borders, labeled 'First Name', 'Last Name', 'Phone', and 'Email Address'. Below these fields is a paragraph of text explaining the petition's purpose: 'There is also need for steps to support the people with our latest focus on employment and to bring to bear the rights against Parkinson's including fundraising, campaigning, services, research and volunteering.' At the bottom of the form are two radio buttons labeled 'Yes, send me emails' and 'No', and a dark blue button with the text 'Sign the petition' in white.

Email journey

263  
petition signatures

39%  
email opt in

# Key learnings

## What worked well

Regular, short project group meetings

Tailored journeys

Robust offline, local activity

Bold authentic creative

## What could be improved

Better ways of working with a remote team

Timings