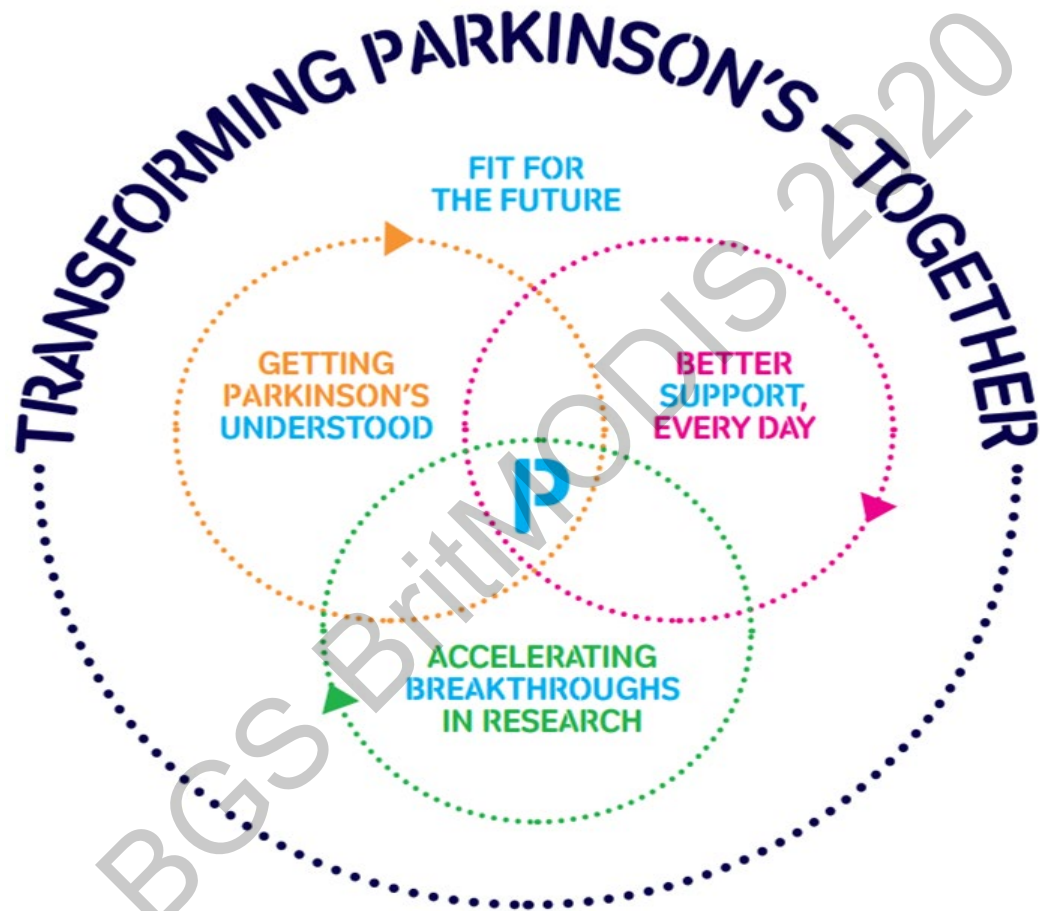


**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

# Transforming Parkinson's Together

## Parkinson's UK Strategy 2020 - 2024

Steve Ford, CEO





Accelerating  
breakthroughs  
in research



**Our pioneering research programme delivers life changing new treatments for people with Parkinson's, who own and shape it every step of the way.**

# Connecting patients with research

In 2017 we surveyed 1526 people affected by Parkinson's. 97% said they would want to hear about opportunities to take part in research within the first year of diagnosis

700 (46%) of then said that they wanted to hear about research from you - their trusted professional - first.

# Meet the Take Part Hub?

Information  
and support



Get Involved



Research



Professionals



About Us



## The Take Part Hub - Find research for you.

Research ranges from at home questionnaires to trialling new treatments. Whatever you're ready for, you can make a difference by taking part.

Your postcode:

Search

# What you can do.

## 1) Use the **Take Part Hub**

[www.parkinsons.org.uk/research/take-part-research](http://www.parkinsons.org.uk/research/take-part-research) -

this supports your competency framework to talk about research.

## 2) Tell your colleagues about the **Take Part Hub**

3 ) Hand out our free *Introduction to taking part* leaflet that you can order on our website .



# Getting Parkinson's understood







**Society understands and cares about Parkinson's.  
More people and organisations are compelled to take  
action, improving life for people with the condition.**



Better support,  
every day





**People with Parkinson's and their loved ones get the right care, support and opportunities to live as well as possible at every stage of the condition.**

# Key results

75% of people at all stages of the condition report that we connect them to the right support and opportunities to live as well as possible

Our service reaches and engages 80% of newly diagnosed people

**PARKINSON'S<sup>UK</sup>**



# Key results

80% of people experience a good or improving Parkinson's service

80% of people can access key, expert members of a multidisciplinary team

# Key results

**80% of people are accessing exercise and physical activity as a clear part of their treatment plan**

**80% of people are benefitting from the support of their peers**



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# PARKINSON'S CONNECT

Creating a new service pathway for people living with  
Parkinson's, their family, friends and carers

# Why do we need to change?

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There are four key drivers:

1. With an estimated 20% increase in the number of people living with Parkinson's over the next decade, our **existing service models are unable to scale to meet new demand**.
2. We want to work as **effectively and efficiently as possible** , whilst increasing our reach and impact. Harnessing digital technologies and new ways of working can help us achieve that
3. **User expectation is changing** and people are looking for support in different ways, we need to be able to change to be there, where we're needed
4. Our current services are **not offering the support needed to family, friends and carers** and they don't recognise us as a charity that's there for them to o

# The Future Service Pathway

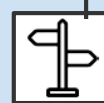
Connecting with everyone affected by Parkinson's at the point of diagnosis



Tailored online and offline information and support, delivered proactively



Early intervention to enable people to take action about their future and fight for their rights



Personal conversation for emotional support

Opportunities to join local events and get involved with Parkinson's UK

Support for family, friends and carers with life ahead

# Progress to date

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## Discover research stage - April - Nov 2019

Collating existing knowledge and doing further research with people with Parkinson's, carers, healthcare professionals and Parkinson's UK service staff across the UK.

Shaping the outline of a new support service pathway.

## Alpha testing stage - Oct 2019 - April 2020

We are testing the following elements of the new service pathway across the UK:

Direct and self  
referral

Service triage

Future planning  
specialist service

Advocacy  
specialist service

Account

The direct referral tool is live in **three locations** and we are testing our other service elements across a range of areas and people.

# REFER SOMEONE TO RECEIVE INFORMATION AND SUPPORT FROM PARKINSON'S UK

Parkinson's UK, the UK's leading Parkinson's charity and can provide you with information and support, they also have specific information for family and friends.

I can refer you both individually, all you need is a mobile phone number or email address.

By being referred you will receive:

- A text or email introducing you to Parkinson's UK
- A link to helpful information about life with Parkinson's
- Information about supporting someone with Parkinson's
- An option to request a call with a Parkinson's UK adviser for general support and advice

► The individual doesn't have access to email

Who would you like to refer? \*



Refer a patient



Refer a family member or friend

Continue

## Direct Referral: what are we testing?

A simple online referral form for people newly diagnosed with Parkinson's and a family member or friend.

This has met governance requirements across three Trusts and is **now live!**

### We want to learn:

- Will this form and process work for consultants and Parkinson's nurses?

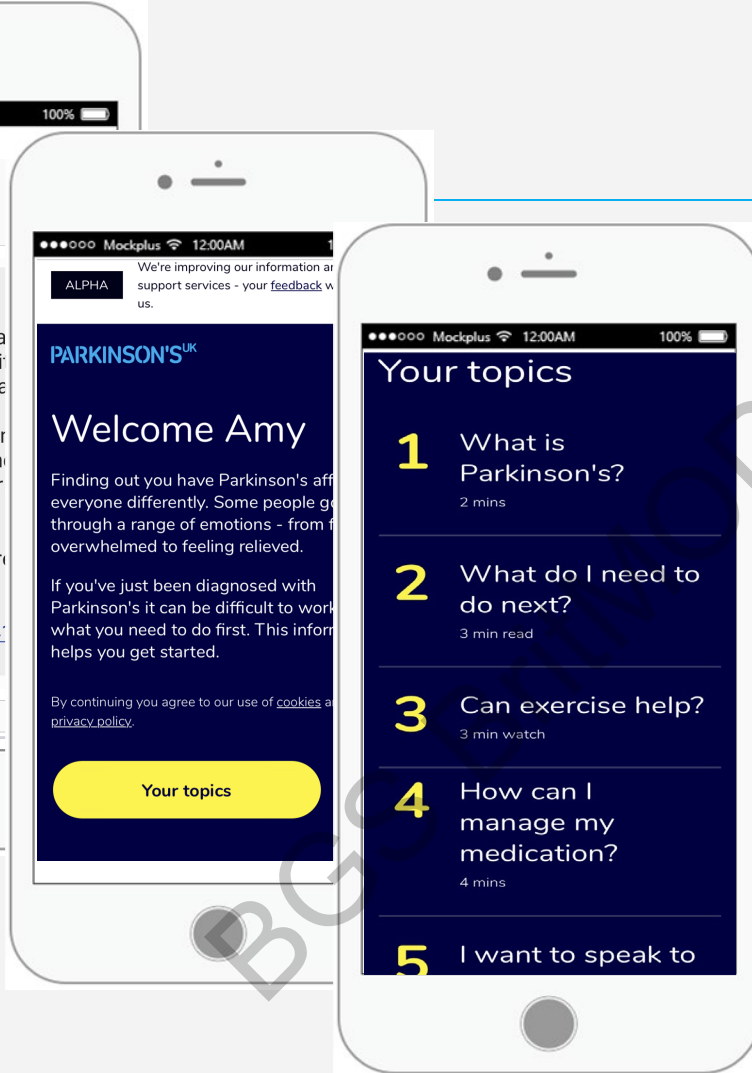
# Direct Referral: what are we testing?

After referral people receive an SMS or email with links to content specific to the person with Parkinson's or loved one.

Print information is still supplied to all patients, whether they are referred or not.

## We want to learn:

- Will people affected by Parkinson's go through the referral process?
- Will they engage with content and find it beneficial?

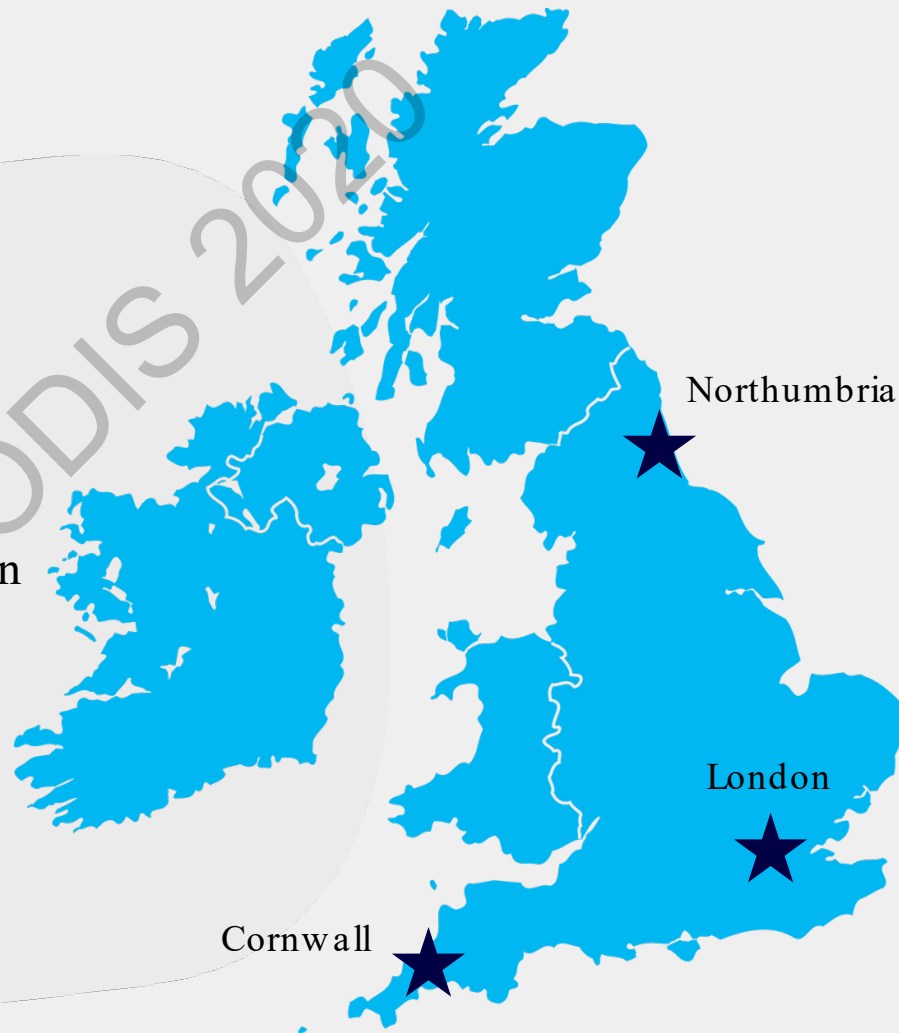




## Direct referral test services....

A huge thank you for the support and enthusiasm of teams at:

- Northumbria Healthcare NHS Foundation Trust
- St George's University Hospitals NHS Foundation Trust
- Cornwall Partnership NHS Foundation Trust



# The first referral into the service...

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- We have now received our first referral and feedback. A family member who said:

**“Was good to read what to look out for”**

*On the ‘What about me?’ page for family and friends*

**“Was good to know there is always someone to talk to”**

*On the ‘Request a call’ page*

# What's next?

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**Beta testing stage** - April 2020 - April 2021

Scale the direct referral tool and other elements of the service pathway to **10 locations** across the UK. Aiming to recruit test sites across different countries, urban vs rural locations, and Parkinson's service models.

**Are you interested in being one of our locations?** Please get in touch via [parkinsonsconnect@parkinsons.org.uk](mailto:parkinsonsconnect@parkinsons.org.uk)

**Transition into new UK -wide service** - April 2021 onwards



# Transforming Parkinson's – Together



**A growing and powerful movement of people is transforming the experience of living with Parkinson's.**









# TEAM PARKINSON'S

**Join the movement that's uniting to end Parkinson's. Forever.**

People with Parkinson's deserve better.

- 1 million people across the UK are affected by Parkinson's.
- 87% of people with Parkinson's have faced harassment and discrimination.
- There's still no cure.

But you can make a real difference.

**[parkinsons.org.uk/teamparkinsons](https://parkinsons.org.uk/teamparkinsons)**

**Join Team Parkinson's**

# THANK YOU

@SteveGFord  
sford@parkinsons.org.uk

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