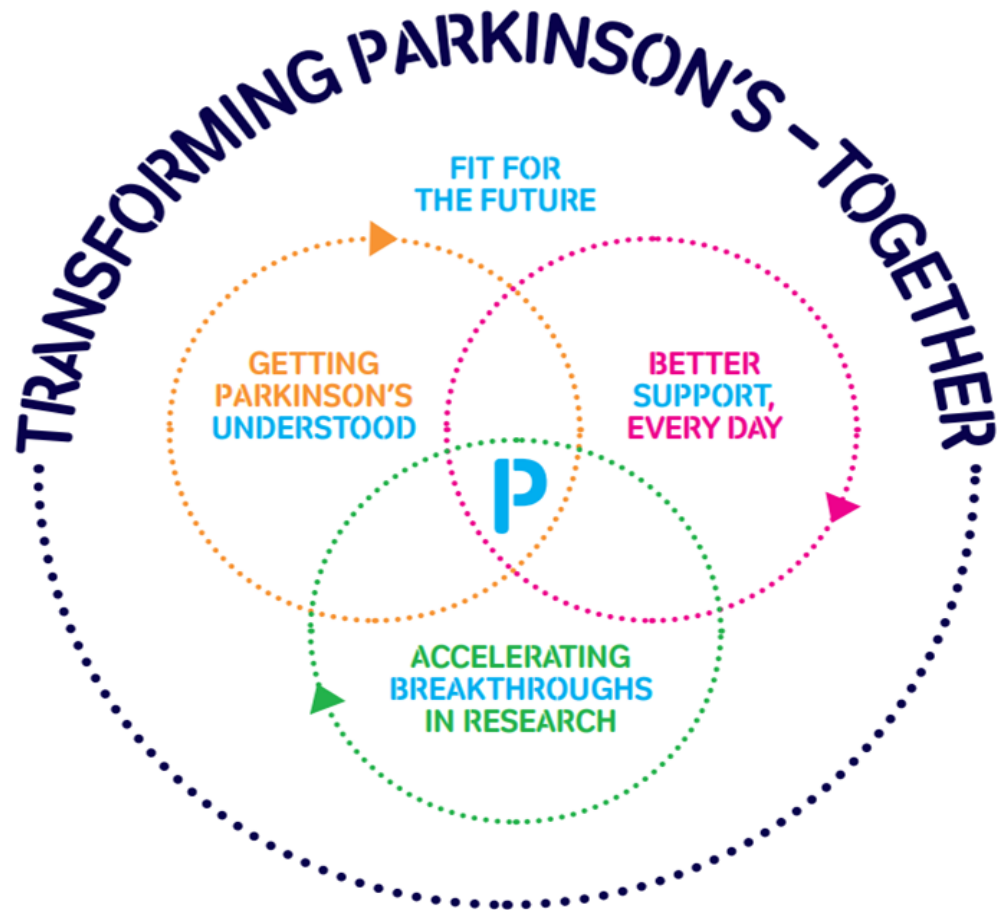


PARKINSON'S^{UK}
SCOTLAND
**CHANGE ATTITUDES.
FIND A CURE.
JOIN US.**

Edinburgh Branch AGM

11th March 2020



There are more people in the UK affected by Parkinson's not engaged with us than there are engaged with us.



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



TEAM PARKINSON'S

click to see
our campaign



View the “click” video
outside this pdf at:
<https://www.youtube.com/watch?v=bNGu-27qP9A&feature=youtu.be>



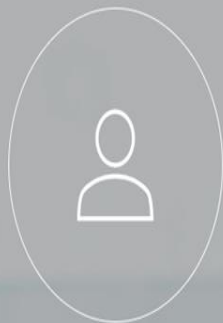
Better support,
every day

A photograph of a group of people, likely at a social gathering or support group. In the foreground, a man with grey hair and glasses is smiling broadly, holding a white mug. To his left, a woman with short white hair and glasses is also smiling. In the background, another man is visible, and a woman is seated to the right. They are all sitting at a table with several white mugs. The background features a large, colorful floral mural. The text is overlaid in a dark blue, bold font.

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.

The Excellence Network

UK Parkinson's Audit 2019



If you are already registered,
click on the icon above to log in

Parkinson's Audit 2019 is live

Over 700 services signed up in 2019!



NHSGGC Parkinson's care streets ahead of UK average

Wednesday, March 4, 2020

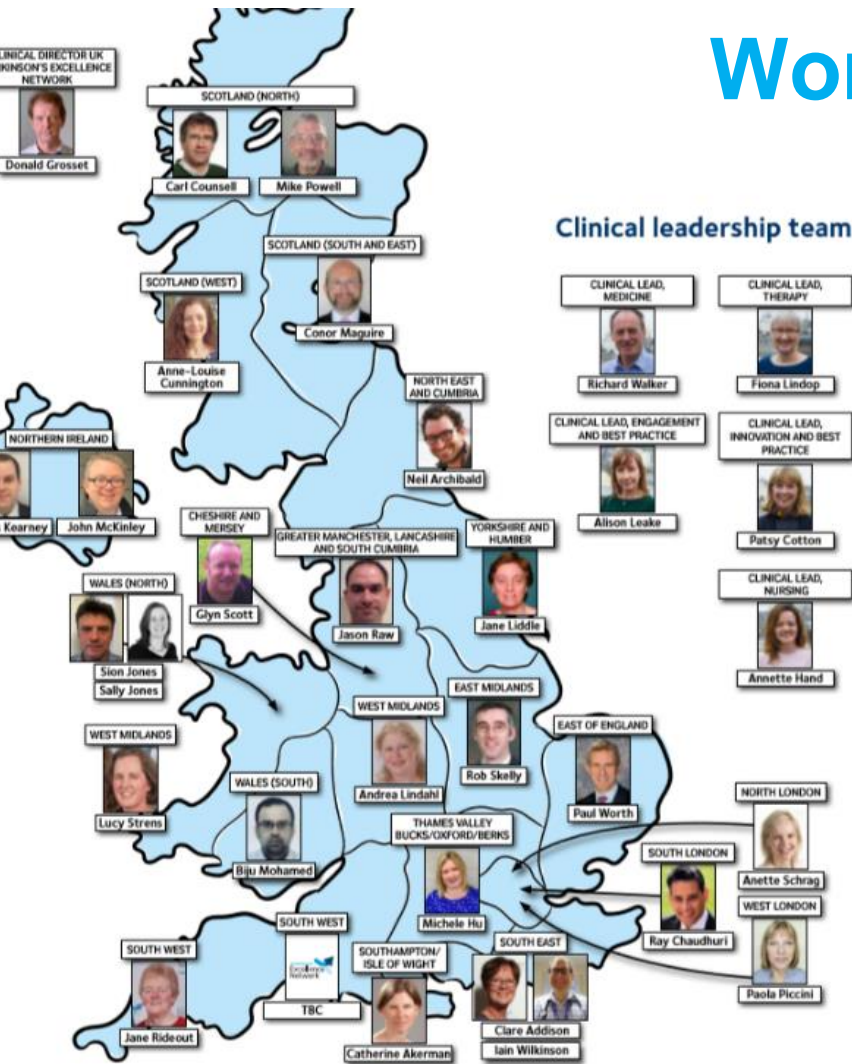
Parkinson's patients in NHS Greater Glasgow and Clyde (NHSGGC) have rated their care as significantly better than the UK average, according to a national audit.

Parkinson's affects one in 375 adults in Scotland. UK-wide Parkinson's Audit of patients showed far higher satisfaction rates in NHSGGC, compared to the rest of the country, in almost every element of their care.

Patients were asked to rate the quality of care from their doctor. In the UK as a whole, 58% of patients

- 76 Services 2019
- Improvement plans & Focus
- Therapists engaged
- Orkney & Shetland nurses.

Working together for change



- 22 regional groups
- 8 working groups inc:
 - Mental Health Hub
 - DBS Network
 - Exercise Hub
 - Pharmacy Network



2019 Audit areas for improvement

Specialised multidisciplinary working



Standardised practices



Communication and information sharing



Medicines management



Supporting the workforce

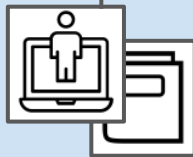


The Future Service Pathway

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



Tailored online and offline information and support, delivered proactively

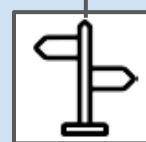


Early intervention to enable people to take action about their future and fight for their rights



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



The workstreams

Alpha one

The Direct Referral Product

(design and develop an end to end journey to test in three locations)

Alpha two

Future planning service

(to design tests for FP service and determine whether it works and what it should look like)

Alpha three

Advocacy service

(to design tests for Advocacy service and determine whether it works and what it should look like)

Alpha four

Service triage

(to design tests for triage to be integrated into MVP)

Alpha five

Newly diagnosed programme

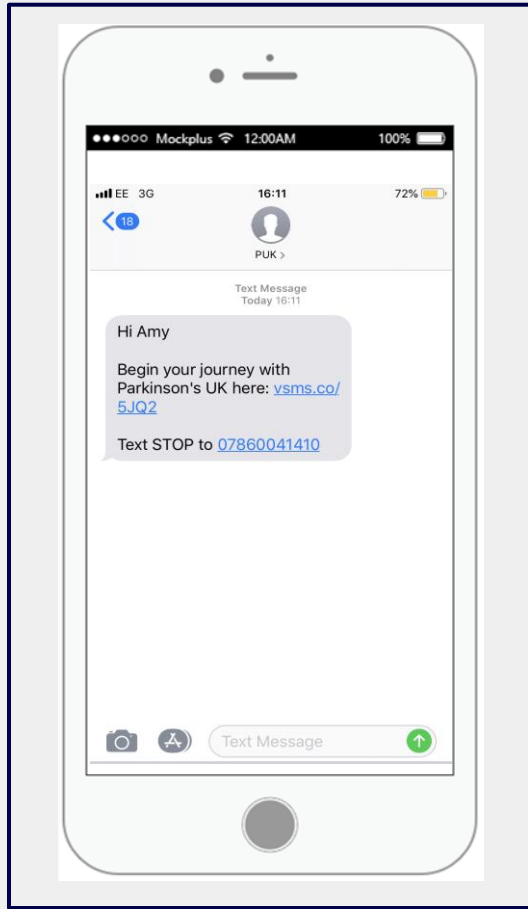
(to design and test online and event content)

Technical design discovery

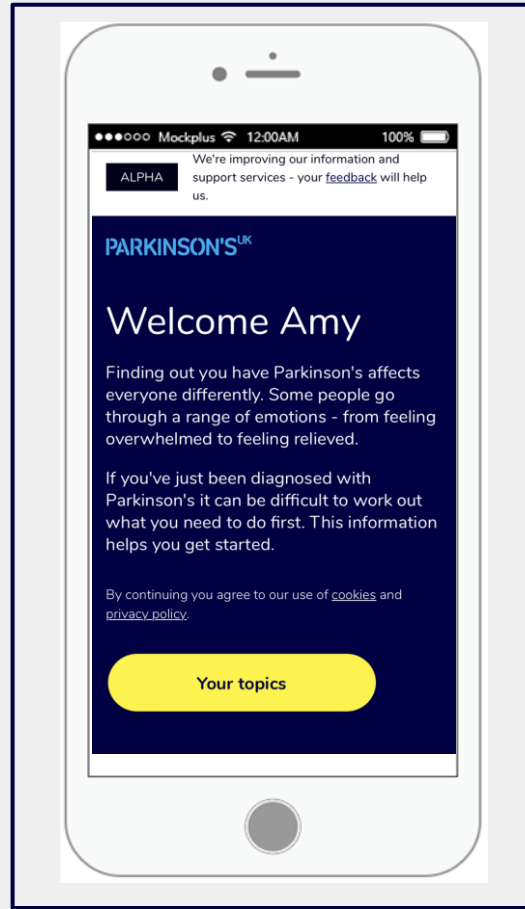
(To design a technical approach giving direction for the architecture and future technical roadmap of Parkinson's Direct)

Strategy, delivery and partnerships

(To develop a three year roadmap, plan Beta and identify and develop potential Partnership opportunities (i.e. Health tech, NHSX, sector partnerships)



Text message received by person referred from Healthcare professional

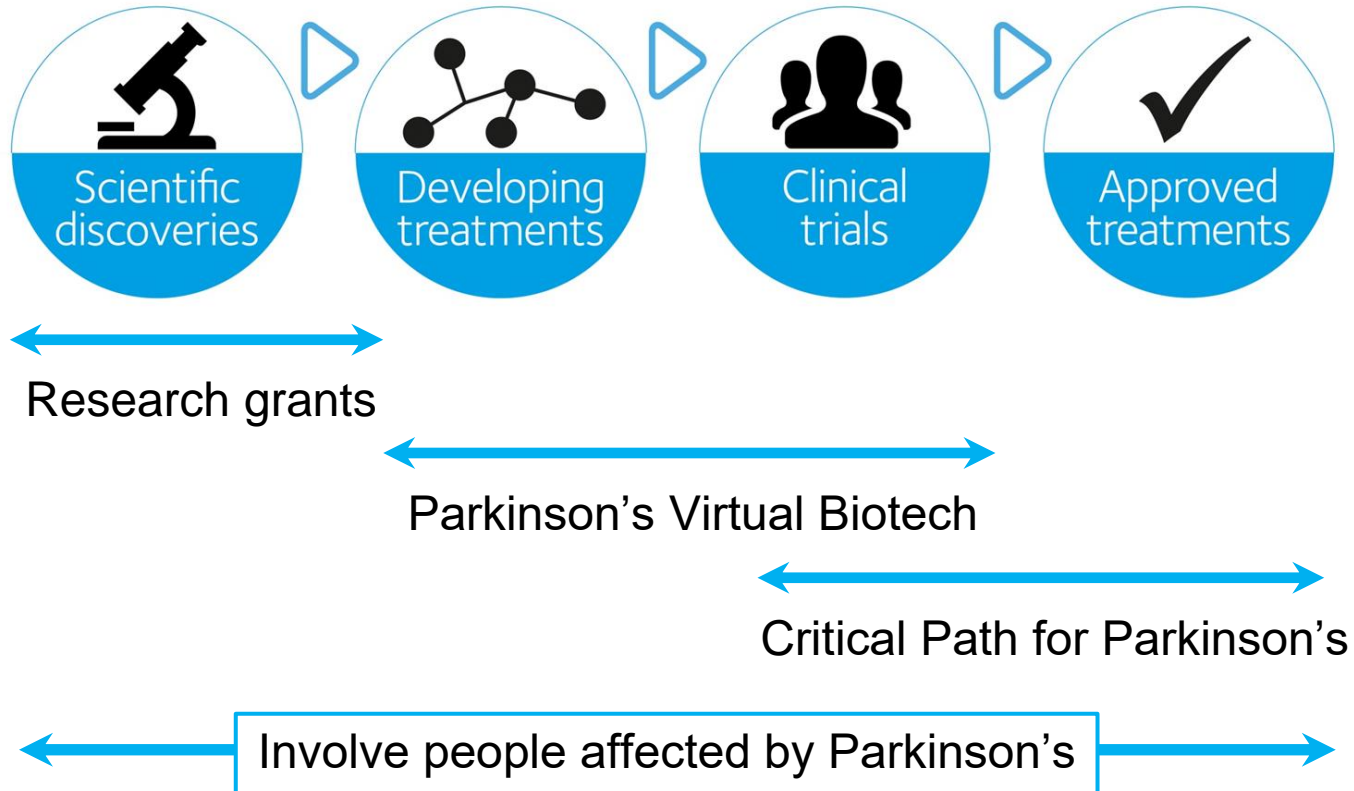


Welcome screen seen by clicking on the link within the text message



By clicking on 'Your topics' on the welcome screen the user is presented with a list of topics

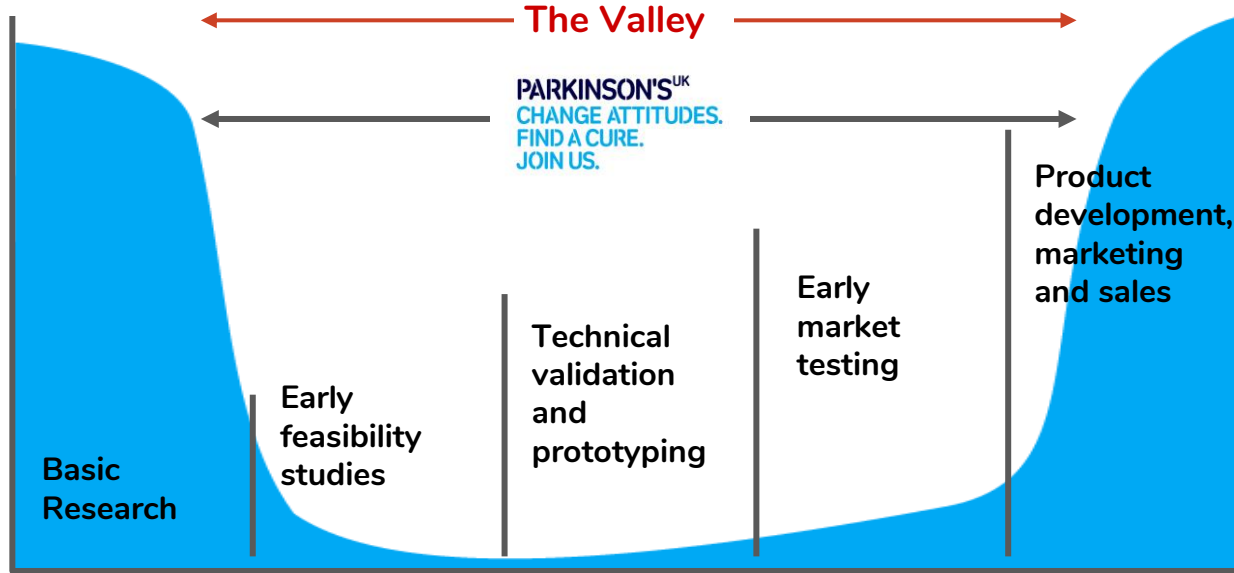
Our research:



Broken pipeline of drug development

Solution: The Virtual Biotech funding model

Government and
Foundation grants



Industry and
VC funding

New funding £5-6m a year



6 of the 45 (Total £16.24M) Parkinson's UK funded projects
- Total value £5.5M for Scottish Grants
13% of the projects but 34% of the funding
8.2% of the UK populations is based in Scotland

25	Project name	Tracking Parkinson's (PROBAND) (J-1101)
Lead researcher		Professor Donald Grosset
Start and end date		Oct 2011–Nov 2020
Location		University of Glasgow
Cost		£3,411,807
Type: Cure		Stage: Scientific discovery

41	Project name	Tracking Parkinson's: searching for biomarkers (J-1301)
Lead researcher		Professor Simon Lovestone
Start and end date		Apr 2014–Dec 2019
Location		University of Oxford and University of Glasgow
Cost		£749,888
Type: Cure		Stage: Scientific discovery

10	Project name	Understanding how the LRRK2 protein is controlled (H-1701)
Lead researcher		Professor Dario Alessi
Start and end date		Oct 2018–Oct 2021
Location		University of Dundee
Cost		£91,389
Type: Cure		Stage: Scientific discovery

Changes in the LRRK2 gene play a crucial role in the development of rare inherited forms of Parkinson's and cause the LRRK2 protein to be more active than normal. Dario and his team have previously discovered a protein called Rab29 that can control the activity of LRRK2. In this research project, they will look at how Rab29 regulates LRRK2 – which could help in the development of new treatments that target this pathway.

4	Project name	Delivering a collaborative exercise approach for people with Parkinson's (F-1901)
Lead researcher		Julie Jones
Start and end date		June 2019–June 2022
Location		Robert Gordon University
Cost		£240,258
Type: Life		Stage: Clinical trial

23	Project name	Understanding gut bacteria to deliver better treatments (G-1705)
Lead researcher		Dr Maria Doitsidou
Start and end date		Jan 2018–Jan 2021
Location		University of Edinburgh
Cost		£243,128
Type: Cure		Stage: Scientific discovery

30	Project name	Exploring a new treatment for bladder problems (K-1801)
Lead researcher		Professor Doreen McClurg
Start and end date		Sept 2018–Sept 2020
Location		Glasgow Caledonian University
Cost		£6,887
Type: Life		Stage: Clinical trial

Bladder problems, such as a frequent and urgent need to pass urine, affect many people with Parkinson's but current treatment options are limited. Transcutaneous electrical stimulation involves using a device to deliver small electrical impulses to the skin. This approach is sometimes used to address pain but has not been used to treat bladder problems before. This project will test if the treatment can improve bladder symptoms in people with Parkinson's.

Nationally in Scotland



Information and support ▼ Get Involved ▼ Research ▼ Professionals ▼ About Us

PARKINSON'S^{UK} SCOTLAND

Scotland Advisory Group

TEN MEMBER GROUP APPOINTED TO STRENGTHEN PARKINSON'S UK SCOTLAND



Scottish Government's £4.5m plan for neurological care and support

Date
9 January 2020



PARKINSON'S UK SCOTLAND AWARDED OVER £140,000 TO CREATE NATIONAL EXERCISE NETWORK

A large group of people of various ages, including children, adults, and seniors, are participating in a walk or run outdoors. Many are wearing blue t-shirts with white text and race bibs. The scene is set on a dirt path with green trees in the background. The overall atmosphere is positive and active.

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

PARKINSON'S UK SCOTLAND IN 2019

Thank you to everyone who helped make this happen.

Our **8** local advisers supported **1,000** families with Parkinson's.



That's a **20%** increase in tailored support, advice and information.

400+ volunteers helped make everything happen.

3 Scottish research groups are active with a new one likely to start up in the north of Scotland early in 2020.



£700,000

raised in Scotland by our regional fundraising team who supported nearly **400** fundraisers, held **4** walks supported by our volunteers and organised our first Golf Day at Royal Troon.

Across Scotland we now have a network of **57** groups and cafes and there are more than **500** activities available to our community. In 2019, our volunteer-led Scotland Development Team supported new activities including:

5 information events, **3** on the islands reaching 240+ people living with Parkinson's.
6 new Parkinson's Cafes.



Input from **1,600** people with Parkinson's shaped **2** ground-breaking reports on Parkinson's services and our Get It On Time campaign. **2** new Parkinson's nurse posts are being created in Orkney and Shetland as a result of this work.



Volunteers arranged for

90 buildings across

Scotland to light up in blue to mark World Parkinson's Day.



We're now funding **6** research projects in Scotland.

75 services took part in the Excellence Network audit (up 60% from 2017). Events, meetings and digital platforms are helping more than **300** professionals to regularly share what works.



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Find out more and contact us at parkinsonsuk.org/Scotland Follow us on Facebook at Parkinson'sUKinScotland and on Twitter at @ParkinsonsUKSco

 **4,421** people now follow our

Facebook page (up 31%). Our page impressions this year are close to **2M**, up 13% from 2018.

728 media articles mentioned Parkinson's UK this year in Scotland (up 64% from last year). They reached an audience of **52M** (up 24%). The equivalent advertising value rose by 43% to **£1.5M**.





THANK YOU

scotland@parkinsons.org.uk

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