

May 2024

# PARKINSON'S CONNECT AT GREATER GLASGOW AND CLYDE NHS



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

**NHS**  
Greater Glasgow  
and Clyde



Scottish Government  
Riaghaltas na h-Alba

# Parkinson's Connect at Greater Glasgow and Clyde NHS

At the end of the funding period, the vision for Parkinson's Connect remains to provide tailored advice and support to people with Parkinson's and their friends and family.

Parkinson's Connect is a digital offer - connecting people affected by Parkinson's to information and support relevant to their situation and stage of living with the condition. This will run in parallel with our people-led phone and local support services to provide a comprehensive, connected service.

Core elements of the proposal continue to be a direct referral at the point of diagnosis to the trusted advice and support offered by Parkinson's UK.

This product was new to the charity and has been piloted in 7 sites across the UK including the Glasgow Older People's Service South, and Glasgow Neurology Service with great success.

In October 2020, funding was awarded from the Neurological Framework to test Parkinson's Connect within GGC NHS within Neurological and Older persons Services. The total funding was £174,184 with £86,260 to Parkinson's UK and £87,924 to GGC NHS. This enabled both organisations to work in partnership to deliver the Parkinson's Connect Project.

## Key Success Factors

We have tried and tested a few ways of tailoring people's experience once they are referred to Parkinson's UK (including a profile and the digital health assistant - personalised email journeys). There has been a lot of learning from these developments and has led us to the latest feature suggestion (the help and support form). Installing the Connect tool at GGC NHS sites and providing information to the people using it. Making the project ready for upscaling, including technical aspects such as automatic referrals to services staff. Increasing the number of local advisers to align with increase in demand. Gathering insights to allow for rollout, including timelines for aspects such as governance and ease of use.

## What is Parkinson's Connect?

Parkinson's Connect is our pioneering programme - a referral tool which allows us to connect with people with Parkinson's **right at the point of diagnosis**. Parkinson's connect works by allowing healthcare professionals to refer people with Parkinson's and their loved ones directly to Parkinson's UK to access the range of support that we offer.

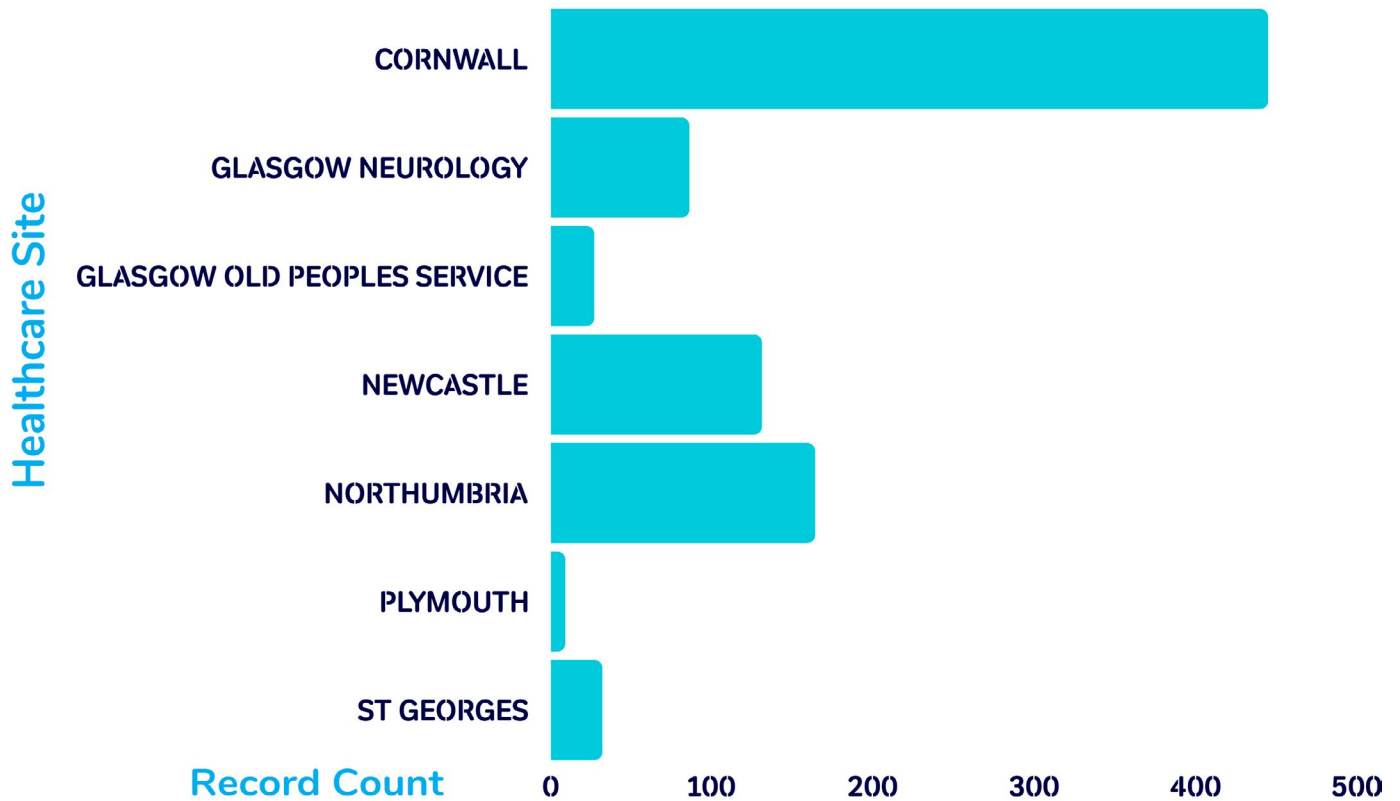
From the moment you're diagnosed, whether online or offline, you can be connected to our support. Our aim is to be there for every single person with Parkinson's. To connect people to information and support that's free of charge and right for each individual.

Visit our webpage here: [parkinsons.org.uk/information-and-support/what-parkinsons-connect](https://parkinsons.org.uk/information-and-support/what-parkinsons-connect)

Target Group	User need	Product features	Business Goals
Newly diagnosed (primary)	Our target group want information on	Automated and secure direct referral mechanism	Way for healthcare professionals to securely refer people to our services and support
Friends and family of the newly diagnosed (secondary)	<ol style="list-style-type: none"> <li>1) What Parkinson's is</li> <li>2) What this diagnosis means for them and their loved ones</li> <li>3) What life could look like post-diagnosis</li> <li>4) They want some form of control over what is happening</li> </ol>	<p>Tailored information for the newly diagnosed (online and via a Helpline advisor)</p> <p>Questionnaire which helps signpost further information and support based on your needs TBD</p>	

## Success Metrics

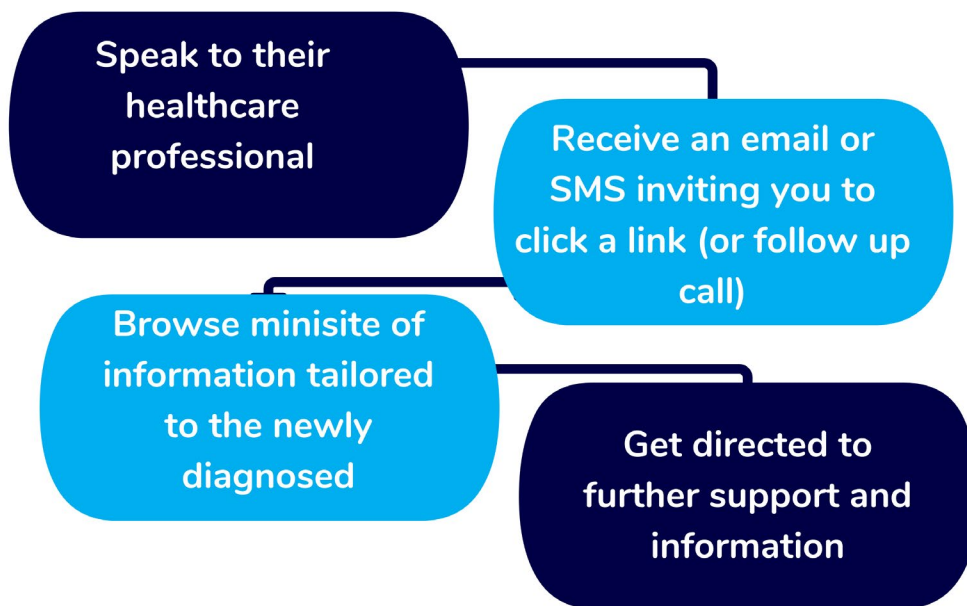
### Direct Referral Enquiries by Healthcare Site



### Objectives and Outcomes

Initial Planned Objective	Phase One Objectives' Status
1. A direct referral product which allows us to reach newly diagnosed people at scale (i.e. a largely automated process).	<b>Fully Met:</b> Automated referral form and process have been rolled out in February 2024.
2. Developed aspects of the personalisation of the direct referral product based on user needs.	<b>Partially Met:</b> Overall direction moved away from gathering personal information and pursuing an email journey, and a “Help & Support” form has been prototyped, awaiting decisions on development.
3. A set of recommendations for scaling based on assessment of the impact and feasibility of onboarding new sites.	<b>Partially Met:</b> Awaiting a business owner to kick start the strategy for scaling which will inform the impact assessment. Onboarded Plymouth Hospital in March 2024.
4. Plan recruitment for the Health Relationships Manager role.	<b>Not Met:</b> Staffing needs still under review, including expectations of the roles and scope of responsibilities.
5. Have recommendations for Phase 2 scope.	<b>Fully Met:</b> Delivery team has presented recommendations including development of “Help & Support” form, awaiting business decision.

## Parkinson's Connect: What it looks like now



## Evaluation Data

Referral Date	Healthcare Site	Record Count
2021	Glasgow Old People Services	0
	Glasgow Neurology	13
2022	Glasgow Old People Services	21
	Glasgow Neurology	48
2023	Glasgow Old People Services	3
	Glasgow Neurology	23
2024	Glasgow Old People Services	5
	Glasgow Neurology	3

## Here's what service managers, consultants and people with Parkinson's have to say about the project:

"A recent audit of referrals to the movement disorder clinic, has highlighted that many of the referrals to the clinic are due to non-medical support needs that could be answered by the high quality information and support provided by Parkinson's Connect. This demonstrates the likelihood that the use of Parkinson's Connect referrals will reduce clinical burden on the GGC Neurology service, with a high potential to reduce waiting-list times."

- **Clinical Service Manager, NHS Greater Glasgow & Clyde**

"Where I've come from we had no resources for Parkinson's and this is an incredible resource. I'm really excited by it."

- **Consultant newly in post, NHS Greater Glasgow & Clyde**

“My experience of being diagnosed with Young Onset Parkinson’s came as quite a shock by letter with very little information about the condition. I wish Parkinson’s Connect was available when I was diagnosed five years ago. Parkinson’s Connect will be a lifeline for People with Parkinson’s and their loved ones. Instead of feeling alone, unsupported, and anxious about the future People with Parkinson’s and their loved ones will be connected and empowered to better manage their health, self-care and live their best life.”

- **Service User Involvement Co-ordinator, Parkinson’s Connect service design team**

“As NHSGGC remobilises following the global pandemic, there is an increasing emphasis within NHS Scotland on promoting supported self-care and self-management to avoid hospital attendances. By implementing Parkinson’s Connect, we hope that we can avoid putting people onto an NHS waiting list for a consultant hospital appointment which maybe of little benefit to them by appropriately triaging the referral to the Parkinson’s Connect team instead. We believe that Parkinson’s Connect will improve patient care by ensuring that our patients are speaking to the person who can best help them in a timely manner, rather than navigating the hospital appointments system by it.”

- **Marjorie Johns, Planning Manager, NHS Greater Glasgow & Clyde**

## Future Plan

We have spoken with two other charities who are undertaking a similar project to share learning and we have promoted this project at Scottish Government webinars encouraging people to adopt similar methods for their work. Our future plans are:

- Regular meetings with GGC NHS staff to plan, give intel and explain system as well as follow up with further information
- 3 new advisers in Scotland to help deal with increasing numbers
- Onboard more sites in Scotland
- Updating and revising microsite
- A more tailored journey from moment of referral through our help and support form

## Financial Transparency

Round (Date)	GGC NHS	Parkinson’s UK	Total
<b>1 - October 2020- March 2021</b>	£14, 883	£12,100	£26,983
<b>2 - March 2021- October 2021</b>	£30,492	£25,410	£55,902
<b>3 - October 2021 - October 2022</b>	£15,609	£13,340	£28,949
<b>4 October 2022 - December 2023</b>	£26,940	£25,410	£63,350

The total awarded was £174,184 over 3 funding rounds. This was split between Parkinson’s UK (£86,260) and GGC NHS (£87,924).

It was used by both to dedicate staff time to deliver and develop this project. Parkinson’s UK spent the funds on their local adviser team (who supports people with Parkinson’s at the point of diagnosis and people were referred) as well as our Service Improvement Manager who was the lead contact between the clinicians and Parkinson’s UK and our parkinson’s connect delivery team/ GGC NHS used towards staff salaries of dedicated admin and clinical support and management.