

Supplementary Material

Real-World Evaluation of the Feasibility, Acceptability, and Safety of a Remote, Self-Management Parkinson's Disease Care Pathway: A Healthcare Improvement Initiative

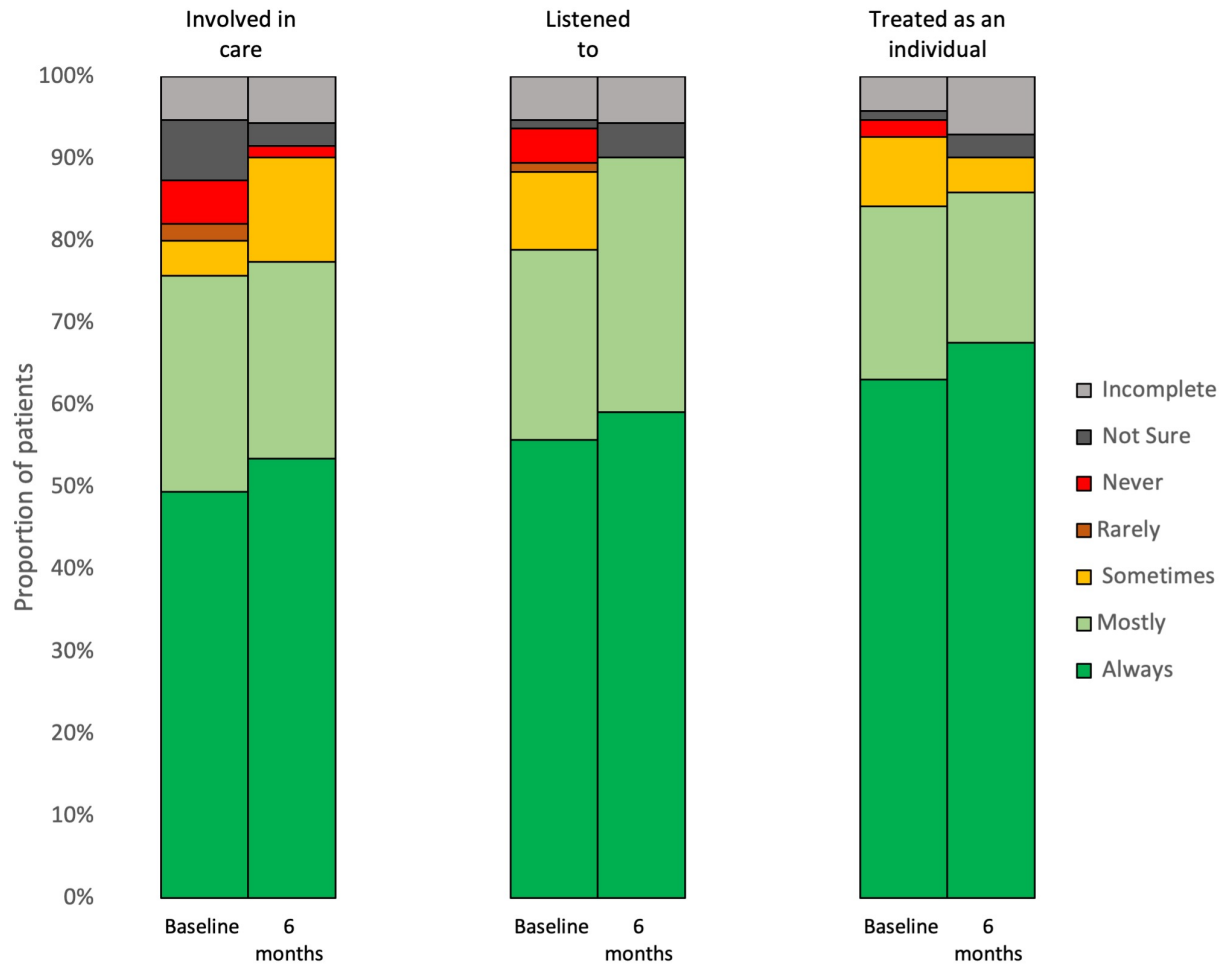
Supplementary Table 1. Semi-structured interview and focus group prompts at baseline and at 6 months.

Patient interviews (baseline)
<ol style="list-style-type: none">1. Have you read the information sheet? Have you any queries regarding this interview?2. Have you signed the consent form and do you understand that you have the right to withdraw at any time during and after this interview?3. Would you tell me how you became aware of this research project?4. How would you describe living with Parkinson's and how does it affect your quality of life?5. Can you describe how often you see your Parkinson's disease nurse and what is your experience of the Parkinson's services?6. Would you explain the Kinetigraph (PKG) and how this is going to assist you and the services you need?7. Would you describe how you would like to see future Parkinson's disease services?8. Is there anything we could do to improve your experience of being involved in this study?
Patient interviews (at 6 months)
<ol style="list-style-type: none">1. How would you describe living with Parkinson's and how does it affect your quality of life today?2. When we last met you described how often you saw your Parkinson's disease nurse and what your experience of the Parkinson's services were. Would you describe these now that you are at the end of this trial?3. At the beginning of the trial you explained the Kinetigraph (PKG) and how this was going to assist you and the services you need? Would you describe how you have experienced both the wearable (PKG) and the services you require?4. Would you describe any changes you have experienced in the Parkinson's disease services?5. Would you describe how you feel about technology and its use in supporting your care?6. Is there anything we could do to improve your experience of being involved in this study?7. Would you promote this research and encourage others to join research studies?
Carer focus group (6 months)
<ol style="list-style-type: none">1. Have you read the information sheet and do you understand what the focus group is designed to do?2. Have you signed the consent form? Do you understand that you have the right to withdraw from this focus group at anytime?

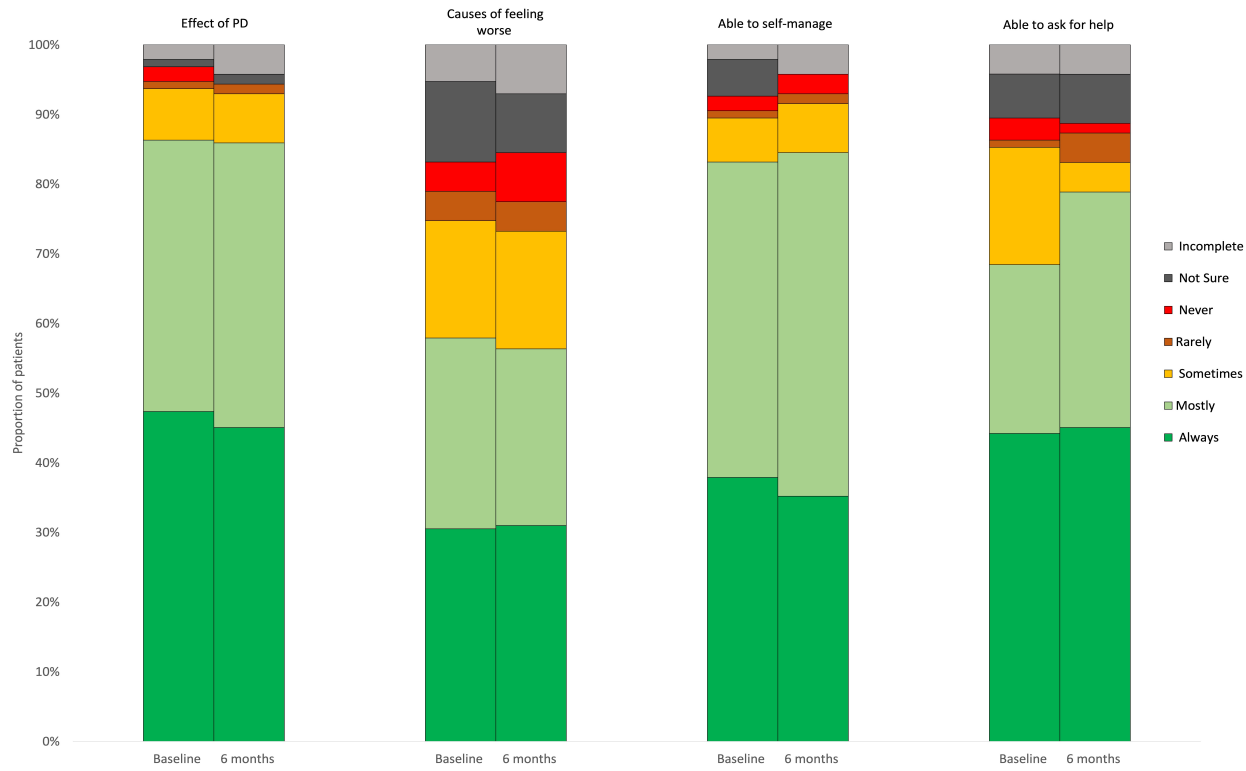
3. Now that your partner/PWP has been involved in the project for some months would you describe how you feel about the person using the wearable device (PKG)?
4. Can you explain if you have noticed any benefits to wearing and using the wearable device?
5. Have there been any problems and if so can you describe these?
6. How do you feel about the Parkinson's support your partner/ PWP has received and is receiving now?
7. Would you describe your quality of life, at this point and has it changed since your partner/PWP started the trial?
8. Is there anything that we, the Research Team, could do to improve the experience of being involved in this research study?

Supplementary Table 2. Service evaluation questionnaires from patients at enrolment and after 6 months on the HBC Pathway.

	Improving	Staying the same - Already good	Staying the same - Needs to improve	Getting worse	Don't Know	Incomplete
Baseline (n=95)	43%	29%	18%	5%	2%	2%
6 months (n=71)	25%	46%	14%	4%	1%	8%



Supplementary Figure 1. Data from service evaluation questionnaires addressing perceptions and experiences of patient-centredness of care. Baseline service evaluation questionnaires (n=95) and after 6 months of care (n= 71). Patient responses to the following: “Do you feel your Parkinson's service involves you in decisions about your care?” (Involved in care), “Do you feel listened to by your Parkinson’s services?” (Listened to), “Do you feel your Parkinson's service treats you as an individual?” (Treated as an individual).



Supplementary Figure 2. Data from service evaluation questionnaires addressing understanding of PD and ability to self-manage. Baseline service evaluation questionnaires (n=95) and after 6 months of care (n= 71). Patient responses to the following: “Do you feel you understand how Parkinson’s affects you?” (Effect of Parkinson’s), “Do you feel able to tell what might be causing your Parkinson’s to feel worse?” (Causes of feeling worse), “Do you feel able to self-manage your Parkinson’s? (Able to self-manage), “Do you understand when to ask for help with your Parkinson’s?” (Able to ask for help).

Over the counter medication

Drug	Type Disp/patch Standard/CR	Dose	Times					

Medication Regime

Is there anything that you would like to let us know about your medication regime? **Yes** **No**

Questionnaire 2: Patient's main concerns

Patient feedback – most troubling symptoms/concerns and additional comments.

Name: _____

DoB: ___/___/___ Hospital No: _____

Date of completion: ___/___/___

Recording period

Is there anything that you would like to let us know about the recording period? **Yes** **No**

Most troubling symptoms/concerns

Do you have any symptoms or concerns that you would like to bring to the attention of the care team/are particularly troubling you? **Yes** **No** *If yes, list the three that are most troublesome.*

Does your care partner have any particular concerns? **Yes** **No**

Please return this feedback form, along with all other questionnaires with your PKG logger device.

Questionnaire 3. Anonymised service evaluation questionnaire

Parkinson's Service Patient Satisfaction Questionnaire

We are interested in how you feel about your current Parkinson's service, and whether it is meeting your needs. There are five sections:

- Section 1 About your Parkinson's service
- Section 5 About you

This information is anonymous and will not affect your care in any way.

Please tick the box in the table which reflects your opinion/experience of the Parkinson's service over the last 12 months.

If you are a carer, you can complete on the patient's behalf.

Date completed:

1. About your Parkinson's Service

Section 1.1: Do you see your Parkinson's Doctor and Nurse frequently enough?

	Yes	No, less than I need	No, more than I need	I don't have one
Parkinson's specialist doctor				
Parkinson's nurse				

Section 1.2: Are you able to contact these people when you need them?

	Easily	Yes, but difficult	No, but have tried	Not tried Don't need
Parkinson's specialist doctor				
Parkinson's nurse				
Occupational Therapist				
Physiotherapist				
Speech and language therapist				

Section 1.3: When being prescribed new medication, do you feel you are given enough information, including potential side effects?

Yes	No	Not sure	I haven't started new medication

Section 1.4: Does your Parkinson's service give you information about:

	Yes	No	Not sure
How to access Parkinson's UK support services			
The role of social workers and other professionals who support people with Parkinson's			
Support for carers			
How to take part in clinical trials			
How to manage your Parkinson's symptoms			

Section 1.5: Do the people in your Parkinson's service ask you about, or listen to your concerns about these matters?

Tick all that apply	Yes	No	Not sure
Balance and falls			
Memory and cognition issues (including dementia)			
Mood, depression, anxiety			
Speech, swallowing or salivary (drooling) problems			
Bladder problems			
Your bowels (constipation)			
Sleep			
Uncontrollable movements (e.g. tremor, dyskinesia)			
Impulse control disorders			

Section 1.6

	Always	Mostly	Some times	Rarely	Never	Not Sure
Do you feel your Parkinson's service involves you in decisions about your care?						
Do you feel listened to by your Parkinson's services?						
Do you feel your Parkinson's service treats you as an individual?						
Do you feel you understand how Parkinson's affects you?						
Do you feel able to tell what might be causing your Parkinson's to feel worse?						
Do you feel able to self-manage your Parkinson's?						
Do you understand when to ask for help with your Parkinson's?						

Section 1.7

Do you feel your Parkinson's service is:	
Improving	
Staying the same – already good	
Staying the same – needs to improve	
Getting worse	

5. About you (the patient)

Section 5.1	
I am the patient	
I am the patient's carer (if completed on the patient's behalf)	

Section 5.2	Under 20	20 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 - 89	Over 90
Age									

Section 5.3	Male	Female	Other	Prefer not to say
Gender				

Section 5.4: Ethnicity	
White (British, Irish, Traveller, any other White background)	
Asia/Asian British/Bangladeshi/Chinese/Pakistani/any other Asian background	
Black/Black British (African/Caribbean/any other Black background)	
Mixed/multiple ethnic backgrounds (mixed White and Black/mixed White and Asian/ mixed any other background)	
Other (Arab/other/prefer not to say)	

Section 5.5	Less than 2	2 – 10	11 – 20	More than 20
How many years ago were you diagnosed?				

Please feel free to write any additional comments below.

