

2015 UK Parkinson's Audit Reference Report

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Appendix A

Definition of phases of Parkinson's

Appendix B

Participating services

Appendix C

Elderly Care and Neurology standards and guidance

Appendix D

Occupational Therapy standards and guidance

Appendix E

Physiotherapy standards and guidance

Appendix F

Speech and Language therapy standards and guidance

Appendix G

Patient Reported Experience Measure
(PREM) questionnaire



UK Parkinson's Audit 2015

- patient reported experience measure (PREM) questionnaire

About the patient

I am the **patient**

I am the **patient's carer** (If so, please complete on the patient's behalf)

1. Age

20 – 29 40 – 49 60 – 69 80 – 89
30 – 39 50 – 59 70 – 79 Over 90

2. Gender

Male
Female

3. Ethnicity

White British Mixed race
Other white background Not stated
Black/Black British Other ethnic group
Asian/Asian British If other (please specify) _____

4. Do you live alone?

Yes No, in a care home
No Other (please specify) _____

5. Approximately how long have you had Parkinson's?

Less than 1 year 3 – 5 years 11 – 20 years
1 – 2 years 6 – 10 years More than 20 years

6. Approximately how long have you been attending your current Parkinson's service?

Less than 1 year 3 – 5 years
1 – 2 years More than 5 years

About your Parkinson's service

7. Do you feel the amount of times you see your consultant or Parkinson's nurse (if you have one) for a review, either at a face-to-face appointment or by telephone, meets your needs?

	Yes	No – less than I need	No – more than I need	No access
Consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parkinson's nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Do you feel able to contact your Parkinson's service for advice in between scheduled reviews?

	Yes	Not sure	No – no access	Not aware of service	Not needed
Service co-ordinator/helpline	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parkinson's nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. How would you rank the quality of service provided by the various parts of your Parkinson's service?

	Excellent	Good	Satisfactory	Poor	No service	Not needed
Consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parkinson's nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10a. Do you feel you were given enough information about Parkinson's when you were diagnosed?

Yes

No

Not sure

10b. Do you feel that you are given enough information about any new medication, including potential side effects?

Yes

No

Not sure/no new medication started

11. Does your Parkinson's service give you information about:

	Yes	No	Not sure
how to access the range of support and information available from Parkinson's UK?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the role of social work for people with Parkinson's and their carers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
support for carers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Has your Parkinson's service ever checked any of the following issues with you and acted on them where necessary? (Please tick all that apply)

	Checked	Acted on	No action needed
Thinking or memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hallucinations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Compulsive disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Swallowing problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Saliva problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bladder problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bowel problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Daytime sleepiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Falls	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tremor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility (walking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility (getting off bed/chair)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
On/off fluctuations and wearing off	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involuntary movements (dyskinesia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Issues with cooking and cleaning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Issues with washing and dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Issues with eating and drinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Issues with function at work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. If you are a driver, have you been given verbal and/or written advice by your Parkinson's service about contacting the DVLA or DVA and your car insurance company?

(If you do not drive, go to question 14)

- Yes
- No
- Not sure

14a. Do you feel your Parkinson's service involves you in decisions about your care?

- Always Sometimes Never
- Mostly Rarely

14b. Do you feel listened to?

- Always Sometimes Never
- Mostly Rarely

15. Have you been admitted to hospital in the last year?

- Yes
- No (If no, please go to question 16)

15b. If yes, how often did you receive your Parkinson's medication at the correct time?

- Always Half the time Never
Mostly Less than half the time Not sure

15c. If you didn't get your Parkinson's medication on time in hospital, to what extent did this affect your condition?

- It had a significant negative effect
It had a negative effect
It had no effect
It had a positive effect
Not sure

15d. Did you want to take your own Parkinson's medication in hospital?

- Yes
No (If no, go to question 16)

15e. Was it possible to take your own Parkinson's medication in hospital?

- Yes
No
Not sure

16. When you are seen by your Parkinson's service, are you treated as a whole person (including other conditions you may have) rather than only as a Parkinson's patient?

- Always Sometimes Never
Mostly Rarely

17. Do you feel that your Parkinson's service is:

- Improving
Staying the same
Getting worse

18. We would be pleased to hear any other views you may have about your Parkinson's service:

Please now put your questionnaire in the envelope provided, seal the envelope and return it to the person who gave it to you.

Many thanks for taking the time to complete this questionnaire.

Appendix H

PREM – Qualitative report
on free-text comments

Appendix I

Acknowledgements