

HENDERSON, L., DUNDAS, F., FORBES, J., HARVEY, A. and NORRIS, S. 2015. Evaluation of Parkinson's 'Care of the elderly' out-patient clinics: perspectives from patients, carers and staff. Aberdeen: Clinical Effectiveness Team, NHS Grampian.

Evaluation of Parkinson's 'Care of the elderly' out-patient clinics: perspectives from patients, carers and staff.

HENDERSON, L., DUNDAS, F., FORBES, J., HARVEY, A. and NORRIS, S.

2015



Evaluation of Parkinson's 'Care of the Elderly' Out-patient Clinics: Perspectives from Patients, Carers and Staff

July 2015

- *Louise Henderson, Lecturer in Adult Nursing, Robert Gordon University, Aberdeen (Previously Parkinson's Specialist Nurse, NHS Grampian)*
- *Freda Dundas, Parkinson's Disease Nurse Specialist, Woodend Hospital*
- *Jacqueline Forbes, Parkinson's Disease Nurse Specialist*
- *Adaline Harvey, Specialist Nurse Team Leader, Woodend Hospital*
- *Sarah Norris, Clinical Effectiveness Facilitator, NHS Grampian*

Correspondence to Project Clinical Lead:

*Name: Louise Henderson
Address: Lecturer in Adult Nursing
Faculty of Health and Social Care
Robert Gordon University
Aberdeen*

*Telephone: via: 01224 263157
Email: l.c.henderson2@rgu.ac.uk*

Quality, Governance & Risk Unit

Supporting quality and safety

*Produced by the Clinical Effectiveness Team, NHS Grampian,
Summerfield House, 2 Eday Road, Aberdeen, AB15 6RE*

CONTENTS

SECTION 1	
EXECUTIVE SUMMARY.....	3
ERROR! BOOKMARK NOT DEFINED.	
SECTION 2	
INTRODUCTION	7
SECTION 3	
METHOD AND SAMPLE.....	8
SECTION 4	
RESULTS	9
SECTION 5	
DISCUSSION AND CONCLUSION.....	29
SECTION 6	
IMPROVEMENT PLAN.....	35
ACKNOWLEDGEMENTS.....	36
REFERENCES	36
APPENDICES.....	36
DISTRIBUTION LIST	55

SECTION 1

EXECUTIVE SUMMARY

INTRODUCTION

There has been a marked increase in the number of patients presenting with Parkinson symptoms over the past year 2013/2014. Care of the Elderly Parkinson Consultant Clinics are held across Grampian with the frequency varying from twice monthly to every 3 months, dependent on location. Nurse Review clinics would be an option to run in tandem with the Consultant Clinic.

The project rationale was to achieve:

- A more integrated Multi-disciplinary Team (MDT) working,
- Make specialist services more accessible,
- To bring services in line with: Health-Fit vision. (*NHS Grampian, 2010*); QIS Standards for Neurological Care. (*The Scottish Government, 2010*) and NICE Guideline 35: Parkinson's Disease Management. (*National Institute for Clinical Health and Excellence, 2006*).

The project objectives were:

- To relieve pressure on current Consultant led Clinics and improve access to specialist Parkinson's services, by delivering these services nearer to the patient's own home
- To reduce waiting times for new patients to be seen, and reduce the waiting times for complex patient reviews (by means of relieving pressures on Consultant time and affording the opportunity to develop 'urgent review' clinic slots
- To potentially cut down on avoidable acute admissions to hospital
- To improve the patient out-patient clinic experience.

Aim of the audit was to create a questionnaire to obtain patient, carer and staff clinic experience to:

- Establish current patient/carers/staff experience
- Identify if non-motor symptom assessments were carried out
- Establish willingness of patient/carers to attend/support Nurse Review Clinics
- Establish which professionals carers/patients would like to see at Clinics

METHOD

Care of the Elderly Parkinson's Consultant Clinics currently take place in Banchory, Fraserburgh, Inverurie, Peterhead and Woodend. Banchory is the only multi-disciplinary clinic where along with a Consultant and a Nurse, there are a Parkinson's Nurse Specialist, a Physiotherapist and an Occupational Therapist.

Separate Patient and Carer Experience Questionnaires for feedback, to support the continuation of the Multi-disciplinary Nurse Review Clinic service, were created. These were piloted at a Woodend and a Banchory (Multi-disciplinary) clinic during January and February 2014. Each patient and carer attending the clinic was asked if they would like to provide feedback on their experience of the clinic. After the pilot, no changes were required to the questionnaire, the main audit was due to run at clinics between April and September 2014, but was extended until November 2014, as attendance numbers were low along with the Parkinson's Nurse Specialist being unable to be at the clinic.

A Staff Experience Questionnaire was also developed for use in each Clinic. It was accepted that some staff may well complete multiple questionnaires, but it was felt that a useful comparison of experiences could be made between the non-multidisciplinary and multidisciplinary clinics.

After the pilot, a scoping SBAR report was produced and was presented to the Management Team at Woodend Hospital in April 2014, by the Parkinson's Nurse Specialist Project Lead, to provide progress on the pilot stage of the project.

In total **49** Patients, **25** Carers and **31** Staff completed questionnaires.

RESULTS

Patients (n=49)

- **71.4%** (35) travelled less than 10 miles, with **57.1%** (20) of those travelling less than 10 miles attended an Aberdeenshire local clinic
- **22.4%** (11) were seen in Banchory (Multidisciplinary), **36.7%** (18) at Peterhead and **40.8%** (20) at Woodend.
- **8.2%** (4) saw an Occupational Therapist, and an additional **12.2%** (6) said they would have liked to have seen one
- **8.2%** (4) saw a Physiotherapist and an additional **6.1%** (3) said they would have liked to have seen one; also **14.3%** (7) said they would have liked to have seen a Parkinson's Nurse Specialist
- **69.4%** (34) stated the health professionals introduced themselves, **75.5%** (37) were given explanations in a way they understood, **89.8%** (44) were given the opportunity to ask questions, for **93.9%** (46) the health professionals listened to what they had to say and **59.2%** (29) patients who had anxieties, had them addressed
- **53.1%** (26) stated the health professionals discussed "Non-Motor Symptoms" with them
- **67.3%** (33) received information about their condition at the clinic; with **38.2%** (18) receiving it verbally, and **65.3%** (32) said the information met their needs
- **77.6%** (38) were 'Very Willing' or 'Willing' to attend a Nurse Review Clinic, run by Parkinson Nurse Specialists, between annual Consultant appointments
- **95.9%** (47) said their overall experience at clinic today was 'Very Good' or 'Good'

Carers (n=25)

- **60.0%** (15) of questionnaires generated were from Woodend, **36.0%** (9) from Peterhead and **4.0%** (1) from Banchory
- **52.0%** (13) were a Spouse/ Partner and **32.7%** (10) were a family member or relative
- **4.0%** (1) saw an Occupational Therapist and an additional **8.0%** (2) said that they would have liked the opportunity to see one
- **0%** (0) saw a Physiotherapist. **8.0%** (2) said that they would have liked the opportunity to have seen one
- **16.0%** (4) stated they would have liked the opportunity to see a Parkinson's Nurse Specialist (PNS)
- **76.0%** (19) stated the health professionals introduced themselves, **96.0%** (24) were given explanations they understood, **96.0%** (24) were given the opportunity to ask questions, for **96.0%** (24) the health professionals listened to what they had to say and **52.0%** (13) where applicable had their anxieties addressed
- **44.0%** (11) of health professionals discussed "Non-Motor Symptoms" with the carers
- **48.0%** (12) stated they received information on the condition at the clinic; with **32.0%** (8) receiving it verbally, and **91.7%** (11) said that it met their needs

- **80.0%** (20) stated that they would be 'Very Willing' or 'Willing' to attend a Nurse Review Clinic, run by Parkinson Specialist Nurses, in between annual Consultant appointments
- **88.0%** (22) stated their overall experience at clinic was 'Very Good' or 'Good'

Staff (n=31)

- **48.4%** (15) of questionnaires generated were from Banchory Clinic, **29.0%** (9) from Peterhead and **22.6%** (7) from Woodend
- **83.9%** (26) stated the Clinics started on time, and **6.4%** (2) said that they ran over.
- **58.1%** (18) provided verbal information only, to patient/carers, with an additional **22.6%** (7) providing both written and verbal. **32.3%** (10) provided contact details for support
- In total **36** referrals were made to other health professionals present in clinic and **25** referrals were made outwith, for those not present at clinic
- **74.2%** (23) stated, where Multi-disciplinary Team members were not available, it would have been beneficial to have had access to them in the clinic
- **25.0%** (7) discussed Non-Motor symptoms with all the patients they saw
- **100%** (15) agreed that the Banchory Clinic arrangements were effective for patients, **42.9%** (3) at Woodend and **22.2%** (2) at Peterhead
- **58.1%** (18) agreed the current clinic arrangements met the needs of the patients, **35.5%** (11) the carers and **35.5%** (11) the health professional clinical goals for patients
- **100%** of responses from medical staff (n=13) identified that they would be happy for a competent qualified PNS to see patients between annual reviews and to adjust medication. **92.3%** (12) of medical staff were happy for PNS to discontinue medication and **53.9%** (7) were happy for PNS to prescribe medication
- **70.8%** (22) of staff rated their experience in clinic as 'Very Good' or 'Good' and **22.6%** (7) said it was "Okay"

CONCLUSION

From the responses received it has been identified that the care delivered at the clinics is person centred. Patients present with diverse and complex health needs and the Clinical Teams manage demanding drug regimes, and non-medication related issues. Treatment is specifically tailored to meet the needs of each individual patient; and the multi-disciplinary clinics, at full complement are of particular benefit to both patients and carers. However, a holistic approach is not entirely being achieved, as multi-disciplinary assessments are not always being conducted by the team. Both patients and carers would appreciate greater opportunities to discuss 'non-motor symptoms', preferably with the Parkinson's Specialist Nurse.

All participants, including staff, acknowledge the value of a "One-Stop Local Service" multi-disciplinary team clinic approach. A reduction in the length of time for a referral outwith the clinic, to absent Therapists, will hopefully be achieved, with direct referrals being an option and will reduce the potential risk of falls, injury, fractures and hospital admissions. Patients and Carers alike would welcome the opportunity to discuss issues including Non-Motor symptoms with the Parkinson Specialist Nurses, individually or with the Consultant, if time and the environment allows. Currently, across the clinics this does not appear to be being achieved. Suggestions were made that time spent with the Parkinson's Nurse independent of the Consultant would be beneficial, reinforcing the benefit of an alternating Nurse Review Clinic. Positive feedback supported the proposal of this type of clinic with both Patients and Carers happy to attend and escort attendees to the clinic. The medical staff were happy for Parkinson Specialist Nurses to adjust and discontinue medication. However, further discussion and guidance is required on the prescribing medication procedures.

IMPROVEMENT PLAN

Action

- Dissemination of results – July 2015
- Use findings to inform decision on consistency of future clinic arrangements for: Urgent Review patients, Nurse Review clinics, MDT staffing levels, and access to Therapists. Consideration should also be given to generating 'New' patient slots in PD clinics to accurately monitor new patient referrals – Autumn 2015
- Review information giving processes, and understanding, of both verbal and written; access to alternative forms - website links and support group information – Autumn 2015
- Establish Non-Motor symptoms discussion management, completion of patient Non – Motor symptoms questionnaire; how to best to manage it and who is responsible for reviewing the symptoms with patients– July 2015
- Agree referral process to Therapists when not available at the MDT clinic. Investigate options of combining the Nurse Review clinic with other specialist clinics (combined with Physiotherapy Falls Clinic or Continence Clinic) – Autumn 2015
- Develop Nurse Review Clinics, to allow increase in service provision by the Parkinson Nurse Specialists. Further consultation and review on Skills required i.e. Non medical prescribing, Banding if further development of these clinics to Nurse led clinics is a future service requirement - Ongoing
- Review comments and discuss options to ensure that Clinics meet the needs of all attendees - July 2015
- Review referral to being seen timescales for both New and Review patients and consider developing a referral screening tool to assist with triaging patients – Autumn 2015

SECTION 2

INTRODUCTION

- 2.1 There has been a marked increase in the number of patients presenting with Parkinson symptoms over the past year 2013/2014. Consultant clinics are held across Grampian, but the frequency varies from twice a month to every 3 months, dependent on location. Nurse Review Clinics would be an option to run in tandem with the Consultant clinic.

The project rationale was to achieve:

- A more integrated Multi-disciplinary Team (MDT) working
- Make specialist services more accessible
- To bring services in line with: Health-Fit vision. (*NHS Grampian, 2010*); QIS Standards for Neurological Care. (*The Scottish Government, 2010*) and NICE Guideline 35: Parkinson's Disease Management. (*National Institute for Clinical Health and Excellence, 2006*).

- 2.2 The project objectives were:

- To relieve pressure on current Consultant led clinics and improve access to specialist Parkinson's services, by delivering these services nearer to the patient's own home
- To reduce waiting times for new patients to be seen, and reduce the waiting times for complex patient reviews (by means of relieving pressures on Consultant time) and affording the opportunity to develop 'urgent review' clinic slots
- To potentially cut down on avoidable acute admissions to hospital
- To improve the patient out-patient clinic experience.

- 2.3 Aim of the audit was to create a questionnaire to obtain patient, carer and staff clinic experience to:

- Establish current patient/carers/staff experience
- Identify if non-motor symptom assessments were carried out
- Establish willingness of patient/carers to attend/support Nurse review MDT clinics
- Establish which professionals carers/patients would like to see at clinics

- 2.4 Parkinson Care for the Elderly clinics currently take place in Banchory, Fraserburgh, Inverurie, Peterhead and Woodend. Banchory is the only Multi-disciplinary Clinic, where along with a Consultant and a Nurse, in attendance, there are a Parkinson's Nurse Specialist, a Physiotherapist and an Occupational Therapist.

- 2.5 Timescales required that a scoping SBAR report on the progress of the project has to be completed by the end of March. This was presented to the Management Team, at Woodend Hospital in April 2014 by the Parkinson's Nurse Specialist Project Lead and included the 'pilot' results. The presentation can be found in Appendix 4.

SECTION 3

METHOD AND SAMPLE

- 3.1 Separate questionnaires for Patient, Carer and Staff experiences of the Parkinson Clinic, were created using SNAP™ software. The questions were created to provide feedback to support the continuation of Multi-disciplinary Nurse Review Clinic Service. The questionnaire also met requirements from the National Institute of Health and Clinical Excellence (NICE), Health Improvement Scotland (HIS) and Scottish Intercollegiate Guideline Network (SIGN) SIGN 113 (Diagnosis and pharmacological management of Parkinson's Disease) Guidelines.
- 3.2 The Patient and Carer questionnaires were piloted at: the Woodend Clinic on the 17th January and 5th February 2014 at Banchory. Each patient and carer attending the Clinic were asked, if they would like to complete a questionnaire to provide feedback on their experience, and hand their completed questionnaire to a member of the clinic staff.

The staff questionnaire was for use in each Clinic and therefore the possibility of multiple questionnaires being completed was acknowledged, but it was considered a useful comparison of experiences between the non-multidisciplinary and multi-disciplinary clinics. Staff questionnaires were completed at the end of each clinic and sent through with the attendee questionnaires to Clinical Effectiveness.
- 3.3 Initially the audit was due to run at clinics held between April and September 2014. Due to attendance numbers being less than expected for the pilot sites, and being a Parkinson's Nurse Specialist down in some Clinics, it was decided to continue to distribute questionnaires at Banchory, Peterhead and Woodend until November 2014
- 3.4 Questionnaires were completed from **14** clinics, (located in Banchory, Woodend and Peterhead) between the audit period, April to November 2014. Six further clinics ran at Inverurie and Banff, during the audit period, but these were not audited.
- 3.5 The completed questionnaires were sent to Clinical Effectiveness Team for analysis. In total **49** Patients, **25** Carers and **31** Staff completed questionnaires. A response rate cannot be calculated as the numbers of patients/carers attending the clinic was not recorded.

SECTION 4

RESULTS

4.1 The results are divided into three sections, Patient, Carer and Staff.

PATIENT RESPONSES (n=49)

4.2 Have you had your condition confirmed as Parkinson's Disease by a Doctor in the Clinic? If Yes, related response results are shown in Table 1.

Table 1 (n=49)

Number (%)			
Yes	If Yes (n=42) , when	No	Not Sure
42 (85.7%)	4 (9.5%) At today 's clinic 38 (90.5%) At a previous clinic appointment	3 (6.1%)	4 (8.2%)

4.3 Who came with you today? Results are shown in Table 2.

Table 2 (n=49)

Who came with you today?	Number (%)
Spouse/Partner	19 (38.8%)
Family member/Relative	16 (32.7%)
Friend	6 (12.2%)
I came on my own	7 (14.3%)
Other (not specified)	1 (2.0%)

4.4 How far did you travel to get to the clinic today? A cross-referenced table with clinic location is shown in Table 3.

Table 3 (n=49)

Distance travelled	Banchory (%)	Peterhead (%)	Woodend (%)	Total (%)
0 to 10 miles	5 (10.2%)	15 (30.6%)	15 (30.6%)	35 (71.4%)
11 to 20 miles	1 (2.0%)	3 (6.1%)	3 (6.1%)	7 (14.3%)
21 to 30 miles	4 (8.2%)		1 (2.0%)	5 (10.2%)
31+ miles	1 (2.0%)		1 (2.0%)	2 (4.1%)
Total	11 (22.4%)	18 (36.7%)	20 (40.8%)	49 (100%)

4.5 Your appointment at the clinic today was a.....?

- New patient visit **2 (4.1%)**
- Follow-up visit **47 (95.9%)**

4.6 Results for “Which of the following health professionals talked with you (did you see) today, to help you manage your condition?”, are shown in Table 4 below, cross referenced with “who you would have liked to have talked with today if you had been given the opportunity?” Both were multiple response questions.

Table 4 Which Health Professional did you see? (n=49) multiple response

Health professionals	Seen today (%)	Did not see (%)	Not Answered (%)	Would liked to have seen (%)
Consultant	43 (87.8%)	5 (10.2%)	1 (2.0%)	4 (8.2 %)
Parkinson’s Nurse Specialist	29 (59.2%)	19 (38.8%)	1 (2.0%)	7 (14.3 %)
Other Doctor	6 (12.2%)	42 (85.7%)	1 (2.0%)	-
Physiotherapist	4 (8.2%)	44 (89.8%)	1 (2.0%)	3 (6.1%)
Occupational Therapist	4 (8.2%)	44 (89.8%)	1 (2.0%)	6 (12.2%)
Other	2* (4.1%)	-	1 (2.0%)	1# (2.0%)

*Heart Condition Nurse; ‘Other’ not specified # Speech and Language Therapist

New Patients Only

4.7 New patients were asked whether the health professionals....? Results are shown in Tables 5a and 5b below.

Table 5a

Did the Health Professionals	Yes	No	Not Sure	Not answered
Establish what you knew about Parkinson’s Disease?	1	-	-	1
Answer any questions you had about Parkinson’s Disease?	1	-	-	1

In addition 8 review patients answered this question. Even though they perhaps had misread the question it was felt useful to include their responses.

Table 5b (n= 10) 2 new and 8 review

Review patients who answered	Yes	No	Not Sure	Not Answered
Establish what you knew about Parkinson’s Disease?	8*	1	-	1*
Answer any questions you had about Parkinson’s Disease?	6*	-	1	2*

Staff at the Clinic

4.8 Did the Health Professionals at the Clinic today.... ? Results are shown below in Table 6.

Table 6 (n=49)

Did the Health Professional	Yes (all of them/ completely) (%)	Some of them/ to some extent (%)	No (%)	Don't know/ Not sure/ Can't remember (%)	Already knew them (%)	Not answered (%)
Introduce themselves?	34 (69.4%)	4 (8.2%)	-	-	7 (14.3%)	4 (8.2%)
Explained things in a way you understood?	37 (75.5%)	7 (14.3%)	-	2 (4.1%)	-	3 (6.1%)
Give you an opportunity to ask questions	44 (89.8%)	2 (4.1%)	-	-	-	3 (6.1%)
If Yes/or Some n=46, were they answered in a way you understood?	38 (82.6%)	5 (10.9%)	-	1 (2.2%)	-	2 (4.3%)
Listen to what you had to say?	46 (93.9%)	1 (2.0%)	-	-	-	2 (4.1%)
Addressed any anxieties you had? #Did not have any anxieties	29 (59.2%)	5 (10.2%)	2 (4.1%)	-	-	4 (8.2%) 9# (18.4%)

4.9 Which health professionals discussed “Non-Motor” symptoms with you today? Results are shown in Table 7, and identifies how many Health Professionals discussed these symptoms with the patient, ranging between 0 (None) and 3.

Table 7 (n=49)

Health professionals	1 (%)	2 (%)	3 (%)	None of them (%)	Not sure (%)	Not Answered (%)
Consultant	13	3	2	12	6	5
Parkinson's Nurse Specialist	5	4	2			
Other Doctor	1	-	1			
Physiotherapist	1	-	1			
Occupational Therapist	-	1	-			
Total	20 (40.8%)	4 (8.2%)	2 (4.1%)	12 (24.5%)	6 (12.2%)	5 (10.2%)

Evaluation of Parkinson's Care of the Elderly Out Patient Clinic: Perspectives from Patient, Carers and Staff

4.10 Was the time given to talk to the...? Results are shown in Table 8.

Table 8 (n=49)

Time given to talk to the...	Too Long (%)	Just about right (%)	Not long enough (%)	Not applicable (%)	Not answered (%)
Consultant	2 (4.1%)	41 (83.7%)	-	2 (4.1%)	4 (8.2%)
Registrar/Other Doctor	-	4 (8.2%)	-	25 (51.0%)	20 (40.8%)
Parkinson's Nurse Specialist	-	21 (42.9%)	1 (2.0%)	10 (20.0%)	17 (34.7%)
Physiotherapist	-	3 (6.1%)	-	28 (57.1%)	18 (36.7%)
Occupational Therapist	-	3 (6.1%)	-	27 (55.1%)	19 (38.8%)

Information

4.11 Did you receive information at this appointment relating to your condition? Results are shown in Table 9a and 9b by patient type and type of information provided.

Table 9a (n=2) Multiple response

New patients	Yes	No
Both Written and Verbal	2	-
Verbal Only	-	-
Written (booklets/leaflets) Only	-	-
Information on websites	-	-
Contact details for support	1	-
Nursing sending out information	1	-

Table 9b shows whether the 47 review patients, received information and in what format they received it in.

Table 9b Review patients (n=47) Multiple response

Did you receive information relating to your condition?	Yes (%)	Already provided (%)	No (%)	Not required (%)	Not answered (%)
Both Written and Verbal	7 (14.9%)	1 (2.1%)	-	-	
Verbal Only	18 (38.2%)	1 (2.1%)	-	-	
Written (booklets/leaflets) Only	1 (2.1%)	-	-	-	
Information on websites	-	-	-	-	
Contact details for support	6 (12.8%)	3 (6.4%)	-	-	
Did not receive any information	-	-	4 (8.5%)	-	
Not required	-	-	-	2 (4.3%)	
Not answered	3 (6.4%)	4 (8.5%)	-	-	2 (4.3%)
Number of Responses	35	9	4	2	2

4.12 Did the information provided (verbally or written) meet your needs? New and Review and results are shown in Table 10.

Table 10 Information met your needs? (n=49)

Did the information you received meet your needs	Yes, completely (%)	To some extent (%)	No (%)	Too early to tell (%)	Not answered (%)
Received at appointment	26 (53.1%)	6 (12.2%)	-	1 (2.0%)	1 (2.0%)
Already provided	4 (8.2%)	3 (6.1%)	-	-	1 (2.0%)
Not required	2 (4.1%)	-	-	-	-
No response	-	-	-	-	5 (10.2%)

Potential Future Clinic Set-Up

4.13 Have you had experience in the past any type of Nurse Review Clinic? Results are shown in Table 11.

Table 11 (n=49)

Experience of 'Nurse Review' Clinics in the past	Number (%)
Yes	11 (22.4%)
No	24 (49.0%)
Not Sure	8 (16.3%)
Not Answered	6 (12.2%)

4.14 How willing are you to attend a Nurse Review Clinic run by Specialist Parkinson Nurses, in between annual consultant appointments? Results are shown in Table 12.

Table 12 (n=49)

How willing..?	Number (%)
Very Willing	24 (49.0%)
Willing	14 (28.6%)
Unsure	2 (4.1%)
Unwilling	1 (2.0%)
Very Unwilling	-
Need to know more before deciding	5 (10.2%)
Not answered	3 (6.1%)

Experience at the Clinic Today

4.15 How would you rate your overall experience at the clinic today? Results are shown in Table 13.

Table 13 (n=49)

Overall Experience at the clinic today	Number (%)
Very Good	34 (69.4%)
Good	13 (26.5%)
OK	2 (4.1%)
Poor	-
Very Poor	-

4.16 Please tell us what has been **Very Good** or **Good** about your experience today?

Very Good

- Can speak about problems with my Daughter/Carer.
- Consultant listened to what I said and gave answers.
- Consultant/Doctor was very pleasant, well mannered and put us at ease
- Detailed and thorough consultation
- Did not have long to sit and wait to see Doctor
- Doctor was very interested in all my symptoms and explained a lot
- Doctor listened to what I had to say
- Everyone concerned listened to what I had to say
- Everyone was very attentive to me
- Everything
- Everything explained clearly
- Explained what I wanted to know
- Finding out about service available
- Good information
- Good information given by consultant
- Good rapport
- Had good discussion with Consultant allayed some of my fears
- No waiting and well informed
- Relaxed atmosphere
- Seeing everyone
- Straight forward talking
- Taken on time. Relevant questions answered
- Understanding
- Very Good the Staff were very pleasant
- Very nice man to my mum (Carer filling in Patient Questionnaire)
- Very professional

Good

- Discussing problems with Nurse (*Stated would have liked to have seen the SPN saw Consultant and Other health professional ? other nurse*)
- Get help from so many people, Nurse, Occupational Therapist and Parkinson's Nurse Specialist
- Getting a chance to see the Consultant and Nurse
- Good Information, Good Feed back
- Nice to have a chat
- The doctor listened to me and I felt reassured.
- Very Good
- We discussed new medication

4.17 Please tell us what has not been so Good?

- Difficulty parking close to the clinic for a disabled person
- Feel the doctor should have a better manner
- I feel quite nervous at having to go to the Clinic. Sometimes I don't like to ask too many questions.

4.18 What would have made your experience better?

- If the doctor had a more pleasant attitude
- Less Waiting Time (Smiley Face)
- More info given related to the side effects of meds and how to deal with aches and pains related to Parkinson's
- Nothing (3); Nothing I can think of; Nothing just fine; Nothing to add
- To have my Parkinson's symptoms relieved
- Would have liked to have had a chat with Parkinson's Nurse
- Would like to have seen SPN.

CARER RESPONSES (n=25)

4.19 Carers were also asked “Which clinic did you attend today?”. Results are shown in Table 14.

Table 14 (n=25)

Banchory (%)	Peterhead (%)	Woodend (%)
1 (4.0%)	9 (36.0%)	15 (60.0%)

4.20 The Carers were asked who they were? Results are shown in Table 15.

Table 15 (n=25)

Who are you ?	Number (%)
Spouse/Partner	13 (52.0%)
Family member/Relative	10 (32.7%)
Carer	2 (8.0%)
Friend	-

4.21 The appointment at the clinic today was as...? Results are shown in Table 16.

Table 16 (n=25)

Appointment Type	Number (%)
New	-
Return	25 (100%)

4.22 Which of the following health professionals talked with you today? Table 17 shows the results along with who would you have liked to have talked to today, if you had been given the opportunity?

Table 17 (n=25) Multiple response

Health professionals	Talked to today (%)	Did not see (%)	Would liked to have talked to (%)
Consultant	22 (88.0%)	3 (12.0%)	2 (8.0%)
Parkinson’s Nurse Specialist	16 (64.0%)	9 (36.0%)	4 (16.0%)
Other Doctor (e.g. Registrar)	4 (16.0%)	21 (84.0%)	-
Physiotherapist	-	25 (100%)	2 (8.0%)
Occupational Therapist	1 (4.0%)	24 (96.0%)	2 (8.0%)
No one – Happy with who I saw	-	-	17 (68.0%)

Staff at the Clinic

4.23 Did the Health Professionals? Results are shown in Table 18.

Table 18 (n=25) Multiple response

Did the Health Professional	Yes (all of them/ completely) (%)	Some of them/ to some extent (%)	Already knew Them (%)	Not answered (%)
Introduce themselves?	19 (76.0%)	1 (4.0%)	5 (20.0%)	-
Explained things in a way you understood?	24 (96.0%)	1 (4.0%)	-	-
Give you an opportunity to ask questions	24* (96.0%)	1 (4.0%)	-	-
If Yes/or Some* (n=25), were they answered in a way you understood?	23 (92.0%)	-	-	2 (8.0%)
Listen to what you had to say?	24 (96.0%)	-	-	1 (4.0%)
Involve you as much as you wanted in decisions about proposed care and treatment?	22 (88.0%)	3 (12.0%)	-	-
Addressed any anxieties you had?	13 (52.0%)	1 (4.0%)	-	5 (20.0%) 6[#] (24.0%)
[#] Did not have any anxieties				

4.24 Please indicate which of the following Health Professionals discussed “Non-Motor” symptoms with you as Carer. Results are shown in Table 19 and identifies how many Health Professionals discussed these symptoms with the carers, ranging between 0 (None) and 2.

Table 19 (n=25)

Health professionals (HP)	1 HP	2 HP	0 (None of them)	Not sure	Not Answered
Consultant	4	7	6	2	6
Parkinson’s Nurse Specialist		6			
Other Doctor		1			
Physiotherapist					
Occupational Therapist					
Total	4 (16.0%)	7 (28.0%)	6 (24.0%)	2 (8.0%)	6 (24.0%)

4.25 Was there time given to talk to the? Results are shown in Table 20.

Table 20 (n=25)

Time given to talk to the...	Too Long (%)	Just about right (%)	Not long enough (%)	Not applicable (%)	Not answered (%)
Consultant	-	21 (84.0%)	1 (4.0%)	2 (8.0%)	1 (4.0%)
Registrar/Other Doctor	-	4 (16.0%)	-	16 (64.0%)	5 (20.0%)
Parkinson's Nurse Specialist	-	14 (56.0%)	-	3 (12.0%)	8 (32.0%)
Physiotherapist	-	-	-	25 (100%)	-
Occupational Therapist	-	1 (4.0%)	-	24 (96.0%)	-

4.26 Table 21 below identifies the responses of 25 Carers for review patients, as to whether they received information at the clinic relating to support/care for someone with a Parkinson's condition and what format they received it in.

Table 21 (n=25)

Did you receive information?	Yes (%)	No (%)	Not answered (%)
Both Written and Verbal	3 (12.0%)	-	-
Verbal Only	8 (32.0%)	-	-
Written (booklets/leaflets) Only	-	-	-
Information on websites	-	-	-
Contact details for support	1 (4.0%)	-	-
Did not receive any information	-	11 (44.0%)	-
Not answered			2 (8.0%)
Total	12	11	2

4.27 Did the information provided (verbally or written) meet your needs? Results are shown in Table 22. The 13 Carers who did not receive information are not included.

Table 22 (n=12)

Did the information meet your needs	Yes, completely (%)	To some extent (%)
Received at appointment	11 (91.7%)	1 (8.3%)

Potential Future Clinic Set-Up (n=25)

4.28 Have you in the past experienced, any type of Nurse Review Clinic? Results are shown in Table 23.

Table 23 (n=25)

Experience of 'Nurse Review' clinics in the past	Number (%)
Yes	8 (32.0%)
No	11 (44.0%)
Not Sure	4 (16.0%)
Not Answered	2 (8.0%)

4.29 How willing would you be to accompany a patient to a Nurse Review Clinic, run by Parkinson Specialist Nurses, in between annual Consultant appointments? Results are shown in Table 24.

Table 24 (n=25)

How willing..?	Number (%)
Very Willing	13 (52.0%)
Willing	7 (28.0%)
Unsure	1 (4.0%)
Unwilling	-
Very Unwilling	-
Need to know more before deciding	2 (8.0%)
Not answered	2 (8.0%)

Experience at the Clinic Today

4.30 How would you rate your overall experience at the clinic today? Results are shown in Table 25.

Table 25 (n=25)

Overall Experience at the clinic today?	Number (%)
Very Good	17 (68.0%)
Good	5 (20.0%)
OK	2 (8.0%)
Poor	-
Very Poor	-
Not answered	1 (4.0%)

4.31 Please tell us what has been Very Good or Good about your experience today?

Very Good

- Able to speak to Consultant and Parkinson's Nurse to discuss other issues
- Any questions we had, have been answered very well
- Doctor plans to change medication
- Everything explained properly
- Everything explained very well
- Friendly helpful staff
- Informative and no waiting
- It was quick
- No waiting time to be seen. Consultant addressed necessary issues - reassured
- Taken into see Consultant on time. Information given to assist
- Very clear and understanding throughout visit
- Very Good
- Very Good - 2 Very Good Health Professionals
- Very good information received
- Very kind and caring

Good

- Very Professional
- We spoke about a different medication
- Explained fully to both of us

4.32 Please tell us what has not been so Good?

- Sorry my ### can't get any more treatment
- We thought we would see the Parkinson's Nurse for the first time. As the Carer I thought this would be helpful for me.

4.33 What would have made your experience better?

- Cup of tea and a biscuit
- More hope for a cure
- Nothing x 4
- Nothing (However they did tick that they would have liked to have seen a Physio and an OT
- Parking at Peterhead is unsatisfactory. Most visits resulted in my mum having to walk long distances. All disabled spaces taken.
- Some Cake Mmmmmm!

STAFF RESPONSES (n=31)

4.34 Staff were asked to complete a questionnaire at each clinic they were in attendance. Therefore, the same staff members could complete more than one questionnaire over the data collection period. Results are shown in Table 26.

Table 26 (n=31)

Banchory (%)	Peterhead (%)	Woodend (%)
15 (48.4%)	9 (29.0%)	7 (22.6%)

4.35 You are? Results are shown in Table 27.

Table 27 (n=31)

You are?	Number (%)
Consultant	10 (32.3%)
Parkinson's Nurse Specialist	7 (22.6%)
Registered Nurse/Staff Nurse	4 (12.9%)
Other Doctor (e.g. Registrar)	4 (12.9%)
Physiotherapist	2 (6.5%)
Occupational Therapist	2 (6.5%)
Auxiliary Nurse	2 (6.5%)

4.36 How many patients did you see? This again is a collection of responses over the data collection period. Results are shown in Table 28.

Table 28 (n=31)

You are?	Total New	Total Review	Overall Total
Consultant	3	36	39
Parkinson's Nurse Specialist	0	21	21
Registered Nurse/Staff Nurse	0	12	12
Other Doctor (e.g. Registrar)	0	6	6
Physiotherapist	1	4	5
Occupational Therapist	5	4	9
Auxiliary Nurse	1	4	5

4.37 Did the clinic start 'On Time' / 'Run Over'? Results are shown in Table 29.

Table 29 (n=31)

Did clinic?	Yes (%)	No (%)	Not sure (%)	Not answered (%)
Start on Time?	26 (83.9%)	5 (16.1%)	-	
Run Over?	2 (6.4%)	22 (71.0%)	1 (3.2%)	6 (19.4%)

4.38 Which staff were in the clinic today? (1 Staff member did not respond to this question) (n=30). Results are shown in Figure 1 and a breakdown in Table 30.

Figure 1

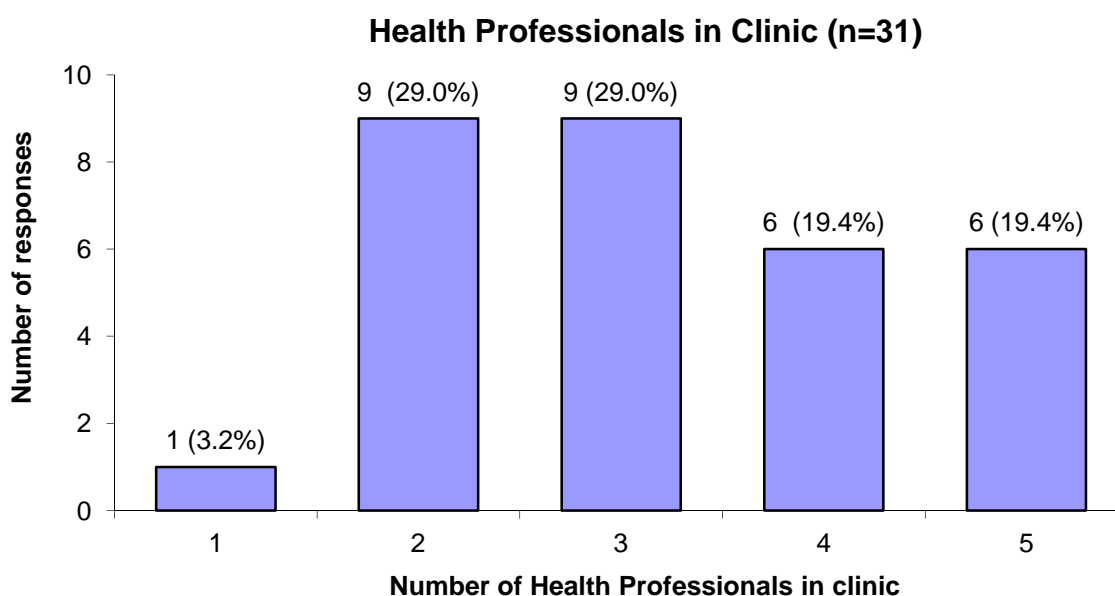


Table 30 Number of Health Professionals Present /Assisting in Clinic (n=31)

Health professional	Number in Clinic				
	1	2	3	4	5
Consultant	1	9	8	6	6
Parkinson's Nurse Specialist		6	8	6	7
Other Doctor			5	1	1
Physiotherapist/Physiotherapy Assist.				5	7
Occupational Therapist/OT Support			2	2	4
Student/Student Physiotherapist			1	1	3
Auxiliary Nurse/Nurse Assistant/Nurse Team Leader/Registered Nurse		3	2	2	3

4.39 Information provided by Staff at the clinics. Results are shown in Table 31.

Table 31 Information provided (Multiple response) (n=31)

Information provided	Number (%)
Verbal Only	18 (58.1%)
Written (booklets/leaflets) Only	2 (6.5%)
Both written and verbal	7 (22.6%)
Information on websites	-
Contact details for support	10 (32.3%)
Not answered	2 (6.5%)

- 4.40 How many patients did you refer to other Health Professionals (HPs) within the clinic today? Results shown in Table 32, show to whom they were referred within the clinic, and can have multiple responses.

Table 32 Referrals within Clinic to other Health Professionals (n=31) Multiple response

Referring Health Professional	Referred to					
	Con	To PNS	Other Dr	Physio	OT	Not stated who
Consultant (Con)		10		4	6	
Parkinson's Nurse Specialist (PNS)				4	4	2
Other Doctor		5				
Physiotherapist (Physio)						1
Occupational Therapist (OT)						

- 4.41 How many patients did you refer to other HPs outwith the clinic today, who and why? Results are shown in Table 33.

Table 33 (n=31)

How many patients did you refer to other HPs out-with the clinic today? by Health professional	Number	Comments
Consultant	7	Physiotherapist not present
Parkinson's Nurse Specialist	13	Physiotherapist not present / SALT (1)
Other Doctor	1	Back to GP
Occupational Therapist	2	Physiotherapist not present
Physiotherapist	2	Occupational Therapist not present

- 4.42 Where additional Multidisciplinary Team members were not available to be referred to within the clinic today, would it have been beneficial for the patient to have had access to them? Results are shown in Table 34.

Table 34 (n=31)

Would it have been beneficial	Banchory (MDT)	Peterhead	Woodend
Yes	7* (22.6%)	9 (29.0%)	7 (22.6%)
Not applicable	6 (19.4%)	-	-
Not Answered	2 (6.5%)	-	-

*Although MDT Clinic – Physiotherapist or OT not present

- 4.43 How many patients did you discuss Non-Motor symptoms with today and how many did you give treatment recommendations to for symptoms? For 3 staff members the questions perhaps were not applicable and therefore did not respond (2 auxiliary and 1 Other Doctor). Results are shown in Table 35.

Table 35 (n=28)

How many patients did you	All (%)	Some (%)	Not Sure (%)	None (%)
.. discuss "Non-Motor" symptoms with today?	7 (25.0%)	16 (57.1%)	-	5 (17.9%)
..give treatment recommendations to for "Non-Motor Symptoms?"	4 (14.3%)	10 (35.7%)	1 (3.6%)	13 (46.4%)

Future Clinic Set-Up:

- 4.44 Staff were asked if they thought the current Clinic arrangements are effective for patients. Results are shown by location, in Table 36.

Table 36 (n=31)

Are current clinic arrangements effective for Patients?	Yes (%)	No (%)	Unsure (%)
Banchory (n=15)	15 (100%)	-	-
Peterhead (n=9)	2 (22.2%)	4 (44.4%)	3 (33.3%)
Woodend (n=7)	3 (42.9%)	2 (28.5%)	2 (28.5%)

- 4.45 Staff were asked if they thought the current Clinic arrangements met the needs of Patients, Carers and their clinical goals. This was a multi-response question. Results are shown in Table 37.

Table 37 (n=31)

Do current clinic arrangements meet the needs of	Ticked Box Agreement (%)	Box not ticked (%)
The needs of Patients	18 (58.1%)	13 (41.9%)
The needs of Carers	11 (35.5%)	20 (64.5%)
Your clinical goals for patients	11 (35.5%)	20 (64.5%)

Comments as to whether the clinics are patient effective, and if they are meeting the needs of the patients, carers and own clinical goals. They have been sorted by location:

Banchory

- Banchory Clinic is in the unique position of offering a MDT approach
- Excellent opportunity for patients to meet MDT and ask questions and by asking patient questions MDT can be involved early on in any assessment and treatments
- Find little support for carers. Carers often express difficulties they have
- For this particular patient's wife was the main carer in my opinion she is under some strain also.
- Get seen holistically
- Good for patients to be seen locally and by MDT
- Ideal clinic set up (Con, PSN and Physio.) ? comments OT normally here
- It gives me an opportunity to briefly review patients and see if they need a physiotherapy assessment/OT treatment appointment arranged. There is insufficient time to do a physical assessment in the clinic. Give patients opportunity to mention their concerns and needs as well as carers and these can be passed on to relevant appropriate professional.
- One stop local service
- OT discusses issues with patient and carers
- Very Good Clinic MDT approach is holistic and patients really enjoy it!

Woodend

- MDT Clinic would be beneficial (Woodend)
- Perhaps for older patients domiciliary visits may be better

Peterhead

- Carers - Further time needed for carers needs to be explored. SALT and Physiotherapy inputs would have been good to meet clinical goals
- Not enough time for holistic assessment

Some staff did not tick any boxes but made comments:

Woodend

- Arrangements effective but care would be improved by presence of Occupational Therapist and Physiotherapist
- I do not think the clinic currently meets the needs of the patients or carers
- More time needed for discussion of symptoms

Peterhead

- Dedicated Physiotherapist and or Occupational Therapy time would be optimal
- Nurse Led clinic would be more beneficial to all
- No to all 3 current clinic arrangements. There was times during the clinic where it would be appropriate to discuss NMS with patients but there was not enough time to do this
- Unsure if needs met
- Unsure

- 4.46 The specific question for Medical Staff (Consultant and Other Doctors); “that if the current 6 month Consultant appointments were changed to annual, would they be happy for a qualified and competent Specialist Nurse Prescriber” to: The results are shown in Table 38, and relate to multiple responses from 2-3 consultants and other doctors working in the various clinic locations.

Table 38 (n=13)

Would you be happy for a competent /qualified PNS to..?	Yes (%)	No (%)	Need to know more (%)
See patients between annual Consultant appointments	13 (100%)	-	-
Prescribe Medication	7 (53.9%)	1 (7.7%)	5 (38.5%)
Adjust Medication	13 (100%)	-	-
Discontinue Medication	12 (92.3%)	-	1 (7.7%)

- 4.47 Staff were asked, in their opinion whether the time allocated to each patient was ...? Results appear in Table 39.

Table 39 (n=31)

In your opinion was the time allocated to each patient	Number (%)
Too Long	1 (3.2%)
Just about right	21 (67.7%)
Not long enough	8 (25.8%)
Not answered	1 (3.2%)

- 4.48 Staff were asked to rate their experience at the clinic today? Results appear in Table 40.

Table 40

Experience	Number (%)
Very Good	10 (32.0%)
Good	12 (38.8%)
OK	7 (22.6%)
Poor	-
Very Poor	-
Not answered	2 (6.5%)

4.49 **What was good**

- Being able to see our patients and witness consultant assessment
- Beneficial seeing patients with MDT, Asking Patient questions can determine if intervention required, explain the role of Occupational Therapist. Doctor is inclusive, realises benefits of MDT at clinic
- Clinic ran to time
- Counselling the best part though, patient does not need any extra medical help
- Cups of coffee - good clinical experience
- Excellent for inter-disciplinary working.
- Fulfilling
- Good to have holistic approach in relaxed atmosphere
- Good to work closely with Consultants - promotes good inter-relations.
- Had Physiotherapist been present - Very good would have been ticked.
- Not too busy, plenty of time to see patients
- Patients' experience of getting to see other members of team, rather than having to wait to be referred.
- Physiotherapist spent time digging deeper into patients Non-Motor symptom issues
- Patient had Non-motor symptoms explored by Physiotherapist and motor symptoms discussed with consultant
- Seeing Consultant thought process or medication/treatment
- Seeing several patients within 1 place. Multidisciplinary Team needs met. Other Health professions present for patient management. Meeting carers at same time. Patient able to discuss their issues
- Support of Parkinson's Disease Nurse Specialist x 5
- Through verbal chat with patient and carer can identify assistance required that may have been overlooked or not identified as Patient may have not been open to Occupational Therapy for some time
- Well paced clinic with excellent Consultant and Nurse Support

4.50 **What has not been so good?**

- Absence of Therapists
- Feel Consultant and Nurse could have more of an input. Issues not mentioned while in with Consultant but when given an opportunity with Physiotherapist were mentioned
- Feel unable to support Carer - who to refer to for support?
- Lack of time with patient - 20 minutes maximum per patient and all staff present here to see patients within this time. Consultant and Nurse in separate consultation. Would be better to all be together for the whole time i.e. 40 mins with Consultant, Parkinson's Nurse Specialist and other health professionals. This would be more informative for all concerned
- Length of time for in depth discussion of symptoms with patients
- No dedicated Therapists
- No holistic assessment of Non-motor symptoms consultations "visited"?
- Not enough time for comprehensive assessment of Non-Motor Symptoms for most patients
- Not having enough time with patients to discuss Non-Motor symptoms and offer support

- Occupational Therapist present but not Physiotherapist. Having to refer patients on to Physiotherapy.
- Physiotherapist not present so had to refer the 4 patients who would have been seen at the clinic to Physiotherapy at another time.
- Poor patient attendance
- Unfortunately Physiotherapist was unable to attend

4.51 **What would have made your experience better?**

- Easier access to Occupational and Physiotherapists
- Fine pieces!!
- Input from Dietician and Occupational Therapist and possible Psychologist - patient very(not readable) and worried
- Longer appointment slots/more time with patients
- MDT input and longer clinic slots
- MDT input from Occupational and Physiotherapists
- Nurse led clinics
- Opportunity for Occupational and Physiotherapy input
- Physiotherapist was not present today, so 5 patients had to be referred to be seen at a later date by the Physiotherapist. Would have referred internal if been present.
- Presence of Parkinson's Disease Nurse Specialist
- Physiotherapist/Occupational Therapist Support

SECTION 5

DISCUSSION and CONCLUSION

Patients (n=49)

- 5.1 **95.9%** (47) of questionnaires were completed by patients attending review appointments. Only **2** were 'New' patients. It was established that "New Patients" are patients who have been seen in a Parkinson's Disease clinic in a new slot. However, it is noted, that this could be an inaccurate reflection upon the amount of "new patients" who are attending the Parkinson's Clinic, as most patients are seen firstly within a Care of the Elderly General Clinic and are subsequently migrated to the Parkinson Disease Clinics in a return slot.

If referrals are sent directly to the Parkinson's Nurse Specialist, ideally patients should be seen within 2 weeks. With satellite Clinics being monthly or so, the Nurses visit the patient at home and then see them again in a Clinic.

Satellite clinics are held twice a month at Woodend, and at the other locations either two or three monthly. The number of 'New' and 'Review' appointments at the actual clinics could not be verified as this information was dependent on the informal completion of a question. The information in this report supports the proposal of Parkinson Nurse Specialist, Nurse Review Multi-disciplinary clinics, being held alternately to Consultant Clinics.

- 5.2 Guidance as to recommended caseload levels is available from National Institute for Clinical Excellence (NICE) ⁽⁴⁾ Scottish Intercollegiate Guidelines Network (2010) 'Diagnosis and pharmacological management of Parkinson's disease. A national clinical guideline' (SIGN guideline 113). Edinburgh: SIGN.

The case load for the Parkinson's Nurse Specialists, (North Aberdeenshire, South Aberdeenshire and Central (Aberdeen City) and Orkney as of 23rd June 2015, covered by 3 nurses (1.94 WTE) was **869** patients.

A Scotland Nurse Report, page 4 quotes "NHS boards should meet the NICE recommendation that each full-time Parkinson's Nurse should have a maximum caseload of **300** people, or **250** in remote and rural areas. A service should be provided to all geographical locations in Scotland." ⁽⁵⁾

- 5.3 **71.4%** (35) of patients travelled less than 10 miles to attend a clinic, of which **57.1%** (20) were to Aberdeenshire clinics (Banchory and Peterhead), reinforcing the provision of person-centred services.

In total **96.6%** (28) of patients, who attended either of the Aberdeenshire clinics (Banchory or Peterhead) travelled 30 miles or less.

- 5.4 The audit set out to obtain feedback from 'Care of the Elderly Clinic' attendees at both types of clinic, "Routine" (Consultant and a Parkinson's Nurse Specialist) and "Multi-disciplinary (Occupational Therapist and/or a Physiotherapist), to provide comparative data. Patient responses from Banchory the Multi-disciplinary Clinic made up **22.4%** (11) of responses; a greater number of responses would have been preferred.

- 5.5 When comparing both types of clinic data, responses as to who the patients had seen, and who they would like to have seen, identified that **18.3%** (9) would have liked to have seen an Occupational Therapist and/or a Physiotherapist. At clinics, where they are not normally present, this requires the patient to be referred onwards, and at the Multi-disciplinary Clinic (Banchory) in some cases, due to staffing issues the Therapists were unavailable. In future, contingencies should perhaps be put in place, if an Allied Health Professional is known to be unable to attend, then a replacement should be found or a 'drop-in' agreement with the local Physiotherapy Department put in place. Staff feedback fully supports the benefits of having Allied Health Professionals present at all clinics providing a "one-stop shop".

An alternative needs to be found when the Physiotherapist is unavailable. Occasionally in some locations a Physiotherapist is accessed for 'urgent' cases by the Parkinson's Nurse Specialist referring the patient to the Physiotherapy Department on the day of the clinic, for immediate assessment. Anecdotal feedback is that patients and carers are more than willing to wait in the Physiotherapy Department to be assessed, rather than having to go home and wait for a Physiotherapy referral appointment. A more direct and formal person centred process needs to be discussed.

Staff feedback supports this issue and indicated where the Physiotherapist was due to be present, but wasn't e.g. on annual leave/off sick, that alternatives have to be found. This of course had an effect on the Multi-disciplinary Clinic feedback, where a Therapist was absent and the need for onward referrals.

At the Consultant and Parkinson Nurse Specialist Clinics, the Nurse sits in with the Consultant in a joint consultation, and rarely is there an opportunity for the Nurse to see the patient separately. At the Multi-disciplinary Clinic the process is the same, but there can be an additional Parkinson's Nurse Specialist available to consult with the patients separately. The Nurse Review Clinics, if they were to be put in place, would provide the opportunity for patients and carers to see the Nurse on a 1:1 basis.

Additional support and information provision in the clinic for patients would be beneficial. In some, but not all clinics, Auxiliary Nurse support is available, assisting with the running of clinics and performing blood pressure readings etc. Discussions have already started as to how to improve the clinic process both for staff and attendees. This includes looking into individual Parkinson Nurse Specialist, patient reviews at the Multi-disciplinary Clinics, as well as supporting the idea of Nurse Review Clinics replacing a 6 monthly appointment in the Consultant Clinic.

- 5.6 Feedback as to how the Health Professionals were perceived by patients was in the majority of statements, positive. However, there were areas in particular that could be reviewed/improved ensuring that Health Professionals:
- introduce themselves where appropriate
 - explain things in a way they are understood
 - answer questions in a way they were understood by patient and carer
 - confirm before patient and carers leave the room that they understand what has been said/explained to them

- 5.7 Non-motor symptoms, i.e. non-movement problems in patients with Parkinson's, ideally should be addressed at each consultation. However, 36.7% (18) patients stated 'None' of the Health Professionals discussed or were 'Not Sure' whether it was discussed. It

is unclear as to why this is the case and further discussion by the Health Professionals, is needed as to whose role it is, and how best to overcome this shortfall. Suggestions that the patients/carer could be asked complete the Non-motor symptoms checklist, either before arrival or at clinic, to act as a prompt to all staff in clinic could be investigated.

- 5.8 Of the **47** 'Review' patients, **65.9%** (31) stated that they had received information in relation to their condition at the clinic, of which **38.2%** (18) had received this verbally and **14.9%** (7) received both verbal and written information. These results are lower than expected. However the question only asked "Did you receive information relating to your condition?". It did not ask whether they had received other information i.e. in relation to useful sources or local group information. The nurses in clinic endeavour to provide contact and support leaflets, but they have to transport these around as storage at locations is unavailable. **19.1%** (9) of patients stated that they did not receive any or did not respond to this question and this needs further investigation. Perhaps the information was provided to the carer or being a review appointment, perhaps they did not need information at that visit. **17.0%** (8) stated that they had already received information, but it was not established, where or from whom they had received it. Discussion as to the type of information provided is ongoing and alternative options of accessing information are being investigated.

Of the information received at clinic or already provided **65.3%** (32) of patients stated it had met their needs completely. However, **18.3%** (9) stated it had met their needs to 'some extent', but none, when asked expanded on this statement as to the additional information they would have liked. It is therefore unclear as to what type of additional information they would have found beneficial. Perhaps a leaflet with useful websites and local support groups would be of benefit, e.g. Parkinson's UK, local focus groups.

- 5.9 Feedback was requested about previous experiences of 'Nurse Review' clinics to establish willingness to see a Parkinson's Nurse Specialist in Clinic between Consultant appointments. **81.8%** (9/11) who had previously experienced this type of clinic stated they would be 'Very Willing' or 'Willing' to attend a Nurse Review clinic. Patients who had never experienced this type of clinic (n=24), **83.3%** (20/24) stated they would be 'Very Willing' or 'Willing', providing positive evidence from both groups towards attending this type of clinic. In total **78.0%** of patients would be 'Very Willing' or 'Willing' to attend a Nurse Review Clinic between annual Consultant appointments.
- 5.10 Overall feedback from the clinics was positive, with **95.9%** (47) of patients stating that it was 'Very Good' or 'Good' which provides reassurance that it is person-centred.

Carer Feedback (n=25)

- 5.11 **36.0%** (9) of Carers stated that they did not see the Parkinson's Nurse Specialist, and **16%** (4) of these would have liked to, with additional comments supporting this. It was unclear as to whether this was due to logistics in the clinic or whether the Nurse was not present. This also links in with staff concerns, as to whether Carers are being given enough support when they attend or enough support is provided afterwards. **3** of the Carers who attended a Woodend Clinic stated they would have liked to have seen an Occupational Therapist and/or Physiotherapist; identifying that there is a demand for Allied Health Professional input, to be available at every clinic.

- 5.12 In contrast to the patient responses, (75.5%), **96.0%** (24) of carers stated that they had had things explained to them in a way they understood. The patient and carer questionnaires were completed independently, so comparisons were not possible. A similar response, **92.0%** (23) was received to whether their questions were answered in a way they understood. These results are higher than from patients, but perhaps clarification is again required that information given is understood.
- 5.13 Carer feedback on discussions about Non-motor symptoms management for the patients identified that **32%** (8) stated that 'None' of the Health Professionals seen discussed this or were 'Not Sure' whether this was discussed. It was not possible, as previously discussed, to pair up responses between carers and patients. Further discussion is required within the Team as to why these discussions are not happening.
- 5.14 **48.0%** of carers received information, lower than that of patients- **67.3 %**. This could be due to the term "Carer" and that 13 patients came on their own or with a friend. A closer analysis looking at responses from Spouse/Partner and Family member/relative may be beneficial. Consistency perhaps is required in information giving. However, the percentage as to whether the information provided had met their needs was **91.7%** for carers and **65.4%** patients.
- 5.15 **32%** (8) of carers had experience of a Nurse Review Clinic and in line with patient responses, **87.5%** (7 out of 8) were 'Very Willing' or 'Willing' to attend this type of clinic and those who had not experienced such a clinic, **81.8%** (9 out of 11) were 'Very Willing' or 'Willing'. It is encouraging to see that both carer and patient are of the same opinion. In total **80.0%** of carers were 'Very Willing' or 'Willing' to attend a 'Nurse Review' clinic in between an annual Consultant appointment.
- 5.16 Overall feed back from the clinics was positive with **88.0%** (22) of carers stating that it was 'Very Good' or 'Good', reinforcing a person-centred approach, but there are areas which require improvement.

Staff (n=31)

- 5.17 The majority of patients who were seen by a Consultant were 'Review' patients (**92.3%** (36/39)) as discussed at point 5.1. Patients seen by the Parkinson's Nurse Specialist (PNS) are classified as review patients, the same as the Consultant, even though they may not have seen the Nurse previously.
- 5.18 Not all clinics started on time as reported by **5** staff members. It is not clear how many clinics this involved as staff members completed a questionnaire for each clinic they were at and some ran-over **6.4%** (2). Reasons as to why they did not start on time were not given.
- 5.19 The number of Health Professionals in the clinics varied between one and five. "Routine" clinics normally have two, a Consultant and a Parkinson's Nurse Specialist, with more staff being present at the Multi-disciplinary Clinic. **36** referrals were made to other Health Professionals within the clinic. With the majority being to the Parkinson's Nurse Specialist, followed by the Physiotherapist and Occupational Therapists. This identifies the benefits of having access to other Health Professionals in clinic.

However, at some Multi-disciplinary Clinics, neither Therapist or only one Therapist was present; requiring an onward referral outside of the Clinic, contradicting the

purpose of such clinics. This could instil a potential delay to being assessed/treated and perhaps putting patients at risk, i.e. of a fall. In total **25** referrals were made 'outwith' the Clinics. Interestingly, the majority, **80%** (20) of these referrals were made from Banchory, the Multi-disciplinary Clinic. The majority of staff specified that they referred patients to Physiotherapy, as no Physiotherapist was available at the clinic. This theory is backed up by staff when asked "Where members of the Multi-disciplinary Team were not present for referral within the clinic on the day", the staff were asked "would it have been beneficial to have had access to them" with **74.2 %** (23) staff responses stating that it would have been.

The Woodend Clinic has now moved to the new "Health Village" location where there currently is no access to Physiotherapists. Further discussions are underway, to identify the possibility of accessing this Service and also how to improve generally the referral pathway, especially for urgent cases, from Parkinson's Nurse Specialists to Community Physiotherapists.

Informal discussions with the Nurses identified that referrals were being made to Physiotherapy via a GP letter. Parkinson's Nurses Specialists, after discussions with Physiotherapy, are now able to make referrals directly over the telephone. The direct access and direct referrals saves precious clinical time as well.

- 5.20 Discussions about Non-Motor symptoms are an important part of the patient's consultation in Clinic. However, only **25.0%** (7) of staff at the clinic discussed symptoms with all patients they saw. Which Health Professional discussed Non-Motor symptoms varied. Options to improve this have already been highlighted.
- 5.21 All the staff (**100%**) completing the questionnaire at the Banchory Clinic stated that the current clinic arrangements were effective for patients. This response supports the benefits of a Multi-disciplinary Clinic and is underpinned by the **35.5%** (11) negative responses and comments from staff at Peterhead and Woodend Clinics.
- 5.22 Staff opinion on whether the current Clinic arrangements were meeting the needs of the patients was sought. Interestingly, only **58.1%** (18) of staff questionnaires agreed, and 13 of these were completed in the Banchory Clinics. There were **35.5%** (11) positive responses for meeting the needs of the Carers (9 from Banchory) with the same number (11) saying it met staff clinical goals, (not all the same responders). Staff raised concerns about the limited support available for Carers and supporting comments are highlighted in the report. Discussions as to how to improve carer support are already taking place.

Multiple questionnaires could have been received from the same member of staff, and was considered beneficial, allowing comparisons between clinic types. It is not known why some staff did not answer, in patient/carer needs being met. It could simply be that they did not agree. Comments supporting responses were provided, prompting further discussions within the team.

In several clinics, comments were made about the interpreted lack of support and attention Carers have and that time should be identified to be able to explore Carer needs further.

- 5.23 **100%** of medical staff stated that they would be happy for the Parkinson's Nurse Specialist to see patients between annual Consultant appointments (in a Nurse Review Clinic) and adjust medication, and **92.3%** were happy for them to discontinue medication. The responses about whether they were happy for them to prescribe medication, identified that **38.5%** (5) would need to know more before making a decision.

Further discussion and consideration of nurse training in preparation for such a development, i.e. nurse prescribing and the advanced nature of the nursing role should be factored into any Improvement Plan, if progressing with a Nurse Review Clinic. It is imperative that the responsibilities and skills required for such a development be adequately reflected, within the level of competency and subsequent banding of nursing staff (See MDT Pilot presentation (shortened version) in Appendix 4).

- 5.24 **70.8%** (22) of staff rated their experience in clinic as 'Very Good' or 'Good'. **22.6%** (7) stated that their experience was OK, 6 of whom were Nurses, with the main problem identified as being 'lack of time', to discuss issues, but these negative comments appear only to be related to Peterhead and Woodend. It has been established in discussions that the appointment times at Banchory are longer which would support the lack of negative comment about insufficient time from this location.

CONCLUSION

From the responses received it has been identified that the care delivered at the clinics is person centred. Patients present with diverse and complex health needs and the Clinical Teams manage demanding drug regimes, and non-medication related issues. Treatment is specifically tailored to meet the needs of each individual patient; and the multi-disciplinary clinics, at full complement are of particular benefit to both patients and carers. However, a holistic approach is not entirely being achieved, as multi-disciplinary assessments are not always being conducted by the team. Both patients and carers would appreciate greater opportunities to discuss 'non-motor symptoms', preferably with the Parkinson's Specialist Nurse.

All participants, including staff, acknowledge the value of a "One-Stop Local Service" multi-disciplinary team clinic approach. A reduction in the length of time for a referral outwith the clinic, to absent Therapists, will hopefully be achieved, with direct referrals being an option and will reduce the potential risk of falls, injury, fractures and hospital admissions. Patients and Carers alike would welcome the opportunity to discuss issues including Non-Motor symptoms with the Parkinson Specialist Nurses, individually or with the Consultant, if time and the environment allows. Currently, across the clinics this does not appear to be being achieved. Suggestions were made that time spent with the Parkinson's Nurse independent of the Consultant would be beneficial, reinforcing the benefit of an alternating Nurse Review Clinic. Positive feedback supported the proposal of this type of clinic with both Patients and Carers happy to attend and escort attendees to the clinic. The medical staff were happy for Parkinson Specialist Nurses to adjust and discontinue medication. However, further discussion and guidance is required on the prescribing medication procedures.

SECTION 6

IMPROVEMENT PLAN

	Action	Date by which action will be accomplished	Person responsible for overseeing action
6.1	Dissemination of results	July 2015	Clinical Effectiveness Team
6.2	Use findings to inform decision on consistency of future clinic arrangements: Urgent Review patients, Nurse Review clinics, MDT staffing levels, and access to therapists. Consideration should also be given to generating 'New' patient slots in Parkinson's Disease clinics to accurately monitor new patient referrals	Autumn 2015	Adaline Harvey Parkinson Disease Nurse Specialists
6.3	Review information giving processes, understanding, of both verbal and written; access to alternative forms - website links and support group information	Autumn 2015	Multi Disciplinary Team Response
6.4	Establish Non-Motor symptoms discussion management, completion of patient Non – Motor symptoms questionnaire; how to best to manage it and who is responsible for reviewing the symptoms with patients– July 2015	June 2015	Multi Disciplinary Team Response
6.5	Agree referral process to Therapists when not available at the MDT clinic and at the Health Village. Investigate options of combining Nurse Review clinics with other specialist clinics (i.e. combined with Physiotherapy Falls Clinic or Continence Clinic)	Autumn 2015	Adaline Harvey AHP Leads Wilma Nicolson
6.6	Develop Nurse Review Clinics, to allow increase in service provision by the PNS. Further consultation and review on Skills required i.e. Non medical prescribing, Banding (as per point 5.22) if further development of these clinics to Nurse led clinics is a future service requirement.	Autumn 2015	Adaline Harvey Parkinson Disease Nurse Specialists Louise Henderson
6.7	Review comments and discuss options to ensure clinics meet the needs of attendees, including equity of appointment times	June 2015	Multi Disciplinary Team Response
6.8	Review referral to being seen timescales for both New and Review patients and consider developing a referral screening tool to assist with triaging patients	Autumn 2015	Adaline Harvey Parkinson Disease Nurse Specialists

ACKNOWLEDGEMENTS

- Thank you goes to all patients and carers attending the Parkinson's Clinics for providing feedback by completing the questionnaire
- Thank you to all member of staff participating in the clinics for completing a staff questionnaire at each location

REFERENCES

- 1 Health-Fit vision. (NHS Grampian, 2010) <http://www.nhsgrampian.org/files/GHP2010-13.pdf> [Accessed 26/2/2015]
- 2 NICE Guideline 35: Parkinson's Disease Management. (National Institute for Clinical Health and Excellence, 2006. <https://www.nice.org.uk/guidance/cg035> [Accessed 26/2/2015]
- 3 QIS Standards for Neurological Care. (The Scottish Government, 2010) http://www.scottishneurological.org.uk/content/res/qis_implementation_plan.pdf [Accessed 26/2/2015]
- 4 Scottish Intercollegiate Guidelines Network SIGN 113 Guideline <http://www.sign.ac.uk/guidelines/fulltext/113/> [Accessed 26/2/2015]
- 5 Parkinson's nurses in Scotland: providing effective, safe, person-centred care <http://www.parkinsons.org.uk/sites/default/files/publications/download/english/scotlandnursesreport>

APPENDICES

- Appendix 1 - Patient Experience Questionnaire
- Appendix 2 – Carer Experience Questionnaire
- Appendix 3 – Staff Experience Questionnaire
- Appendix 4 – Presentation by Louise Henderson (Shortened Version)

Patient Experience of the Parkinson's Disease Clinic



Thank you for agreeing to complete this questionnaire about your experience today at the Parkinson's Disease Clinic. If you require any assistance in filling it in, please do not hesitate to contact a member of staff who will be happy to help. Your responses will help us to ensure that the information and support we provide is of a high standard and beneficial to patients. Please respond to each question by putting a tick in the appropriate box(es). All replies are anonymous and you cannot be identified.

Clinic attended today:

Banchory..... Peterhead..... Woodend.....

The Clinic

Q1a Have you had your condition confirmed as Parkinson's Disease by a Doctor in the Clinic?

Yes No (Go to Q2a) Not sure (Go to Q2a) .

Q1b If Yes, when was this?

At today's Clinic..... At a previous Clinic appointment

Q2a Who came with you today..?

Spouse/Partner Friend.....

Family member/Relative I came on my own.....

Other.....

(Other please specify)

Q2b Approximately how far did you travel to get to the clinic today?

0 - 10 miles ... 11 - 20 miles . 21 - 30 miles . 31 + miles.....

Q3 Your appointment at the clinic today was a ...

First visit (New Patient) Follow-up visit

Q4

Which of the following health professionals talked with you today to help you manage your condition? (Tick all that apply)

- | | | | |
|-----------------------------------|--------------------------|------------------------------------|--------------------------|
| Consultant..... | <input type="checkbox"/> | Other Doctor (e.g. Registrar)..... | <input type="checkbox"/> |
| Specialist Parkinson's Nurse..... | <input type="checkbox"/> | Physiotherapist | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | Occupational Therapist..... | <input type="checkbox"/> |
- (Other please specify)

Physiotherapists treat injury or disease with exercises and other physical treatments to obtain the best physical function.

Occupational Therapist works to help promote health, prevent injury or disability and sustain or restore the highest possible level of independence.

Q5

Which of the following health professionals would you have liked to have talked to today, if you had been given the opportunity?

- | | | | |
|-----------------------------------|--------------------------|------------------------------------|--------------------------|
| Consultant..... | <input type="checkbox"/> | Other Doctor (e.g. Registrar)..... | <input type="checkbox"/> |
| Specialist Parkinson's Nurse..... | <input type="checkbox"/> | Physiotherapist | <input type="checkbox"/> |
| Other | <input type="checkbox"/> | Occupational Therapist..... | <input type="checkbox"/> |
- Please specify

New Patients Only

Q6

At the clinic today, did the health professionals establish what you knew about Parkinson's Disease?

- Yes..... No..... Not sure.....

Q7

Did the health professionals answer any questions you had about Parkinson's Disease?

- Yes..... No..... Not sure..... Did not have any questions

Staff at the Clinic - All Patients

Q8

Did the health professionals introduce themselves?

- | | | | |
|--------------------------------|--------------------------|---------------------------|--------------------------|
| Yes, all of them | <input type="checkbox"/> | Some of them | <input type="checkbox"/> |
| No | <input type="checkbox"/> | I already knew them | <input type="checkbox"/> |
| Don't know/Can't remember..... | <input type="checkbox"/> | | |

- Q9** Did the health professionals explain things in a way that you understood?
- Yes, completely..... To some extent..... Not Sure..... No
- Q10a** Did the health professionals give you the opportunity to ask questions?
- Yes, all of the professionals..... No (Go to Q11).....
 Some of them Can't remember (Go to Q11).....
- Q10b** If 'Yes', or 'Some' to Q10a, were your questions answered in a way you understood?
- Yes..... To some extent..... No Not Sure.....
- Q11** Did the health professionals listen to what you had to say?
- Yes To some extent..... No
- Q12** Were you involved as much as you wanted to be in decisions about your care and treatment?
- Yes To some extent..... No Not sure
- Q13** Did the health professionals address any anxieties that you had? (e.g. 'how will I cope', 'will I be able to work', 'driving', 'changes in roles', 'impact on family'...)
- Yes..... To some extent..... No..... Didn't have any anxieties...

Non-Motor Symptoms: The movement symptoms of Parkinson's Disease are well known. However, non-motor symptoms can sometimes occur as part of the condition and are not related to your mobility or movement.

- Q14** Please indicate which of the following health professionals discussed "Non-Motor" symptoms with you today? (Tick all that apply)
- Consultant..... Physiotherapist..... Not sure.....
 Registrar/other Doctor Occupational None of them.....
 Parkinson's Nurse Therapist.....

Q15 Was the time given to talk to the

	Too Long	Just about right	Not long enough	Can't remember	Not Applicable
Consultant.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Registrar/Other doctor	<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"/>
Physiotherapist	<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"/>

Information:

Q16a Did you receive information at this appointment relating to your condition? (Tick the box that applies to you)

	Yes	No	Already Provided	Not Required
New Patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Follow-up Patient.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q16b If Yes to 16a, in what format were you given the information: (Tick all that apply)

Both written (information booklets) and verbal	<input type="checkbox"/>
Verbal only.....	<input type="checkbox"/>
Written (booklets/leaflets) only	<input type="checkbox"/>
Information on websites that can be accessed.....	<input type="checkbox"/>
Contact details for support (Nurse specialist etc.)	<input type="checkbox"/>

Q16c Did the information provided (verbally or written) meet your needs:

Yes, completely..... To some extent No Too early to tell

If applicable what other information would you have liked:

Potential Future Clinic set-up:

Q17a Have you had experience in the past of any type of Nurse-Led Clinic?

Yes No Not Sure

Q17b On average, patients are reviewed in Clinic on a 6 monthly basis by a Consultant. How willing are you to attend a Nurse-Led Clinic, run by Specialist Parkinson Nurses, in between an annual Consultant appointment?

Very Willing..... Willing..... Unsure
Unwilling Very Unwilling..... Need to know more before deciding.....

Q17c If "Unwilling" or "Very Unwilling" to attend a Nurse-Led Clinic, please feel free to comment:

Experience at the Clinic Today:

Q18 How would you rate your overall experience at the clinic today?
Very Good..... Good..... OK Poor..... Very Poor.....

Q19 Please tell us what has been Very Good or Good about your experience today?

Q20 Please tell us what has not been so good?

Q21 What would have made your experience better?

Thank you for completing the questionnaire. Please place it in the box provided. The results of the audit will be analysed by the Clinical Effectiveness team and will be discussed with the multidisciplinary team and will be fed back to our patients at the clinic.

If you have any questions raised by completing this questionnaire, please do not hesitate to speak to a member of staff.

Louise Henderson
Specialist Parkinson's Nurse

January 2014

Carer Experience of the Parkinson's Disease Clinic



Thank you for agreeing to complete this questionnaire about your experience today at the Parkinson's Disease Clinic. Your responses will help us to ensure that the information and support we provide is of a high standard and beneficial to patients and carers alike. Please respond to each question by putting a tick in the appropriate box(es). All replies are anonymous and you cannot be identified.

Clinic attended today:

Banchory Peterhead Woodend

Q1 Who are you?

Spouse/Partner Carer

Family member/Relative Friend

Other

(Please specify)

Q2 The appointment at the clinic today was as a ...

New patient (first visit) Return patient (follow-up visit)

Q3 Which of the following health professionals talked with you today to help you understand the condition? (Tick all that apply)

Consultant Other Doctor (e.g. Registrar)

Specialist Parkinson's Nurse Physiotherapist

Other Occupational Therapist

Other (please specify)

Physiotherapists treat injury or disease with exercises and other physical treatments to obtain the best physical function

Occupational therapists work to help promote health, prevent injury or disability and sustain or restore the highest possible level of independence

Q4 Which of the following health professionals would you have liked to have talked to today, if you had been given the opportunity? (Tick all that apply)

Consultant.....	<input type="checkbox"/>	Other Doctor (e.g. Registrar).....	<input type="checkbox"/>
Specialist Parkinson's Nurse.....	<input type="checkbox"/>	Physiotherapist	<input type="checkbox"/>
Other	<input type="checkbox"/>	Occupational Therapist.....	<input type="checkbox"/>

Please specify

Please Only answer Q5 and Q6 if the patient you are accompanying is a New Patient:

Q5 At the clinic, did the health professionals establish what you knew about Parkinson's Disease?

Yes..... No..... Unsure..... Not applicable

Q6 Did the health professionals answer questions you had about Parkinson's Disease?

Yes..... No..... Unsure..... Not applicable

Staff at the Clinic:

Q7 Did the health professionals introduce themselves to you?

Yes, all of them.....	<input type="checkbox"/>	Some of them	<input type="checkbox"/>
No	<input type="checkbox"/>	I already knew them.....	<input type="checkbox"/>
Don't know/Can't remember.....	<input type="checkbox"/>		

Q8 Did the health professionals explain things in a way that you understood?

Yes, completely To some extent..... No.....

Q9a Did the health professionals give you the opportunity to ask questions?

Yes, all of the professionals.....	<input type="checkbox"/>	No (Go to Q10)	<input type="checkbox"/>
Some of them	<input type="checkbox"/>	Can't remember (Go to Q10)	<input type="checkbox"/>

Q9b If 'Yes', or 'Some' to Q9a, were your questions answered in a way you understood?

Yes To some extent..... No.....

Q10 Did the health professionals listen to what you had to say?

Yes To some extent..... No.....

Q11 Were you involved as much as you wanted to be in decisions about the proposed/ planned care and treatment?

Yes To some extent No Not sure

Q12 Did the health professionals address any anxieties that you had ? (e.g. 'how will I cope', 'will I be able to work', 'driving', 'changes in roles', 'impact on family'..)

Yes..... To some extent No Didn't have any anxieties..

Non-Motor Symptoms: The movement symptoms of Parkinson's Disease are well known. However, **non-motor symptoms** can sometimes occur as part of the condition and **are not related to the patients** mobility or movement.

Q13 Please indicate which of the following Health Professionals discussed "Non-Motor" symptoms with yourself today (in your role as a "carer")? (Tick all that apply)

Consultant Physiotherapist Not Sure
 Registrar/other Doctor Occupational Therapist None of them
 Parkinson's Nurse

Q14 Was the time given to talk to the:

	Too Long	Just about right	Not long enough	Can't remember	Not Applicable
Consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Registrar/other doctor	<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"/>
Physiotherapist	<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"/>

Information:

Q15a Did you receive information at this clinic appointment relating to support/care for someone with a Parkinson's condition?

Yes No

Q15b If Yes to 15a, in what format were you given the information: (Tick all that apply)

Both written (information booklets) and verbal
 Verbal only
 Written (booklets/leaflets) only
 Information on websites that can be accessed
 Contact details for support (Nurse specialist etc..)

Q15c Did the information provided (verbally or written) meet your needs?

Yes completely To some extent..... No

Too early to tell Unsure Not applicable

Potential Future Clinic set-up:

Q16a Have you had experience in the past of any type of Nurse Led Clinic?

Yes No Not Sure

Q16b On average, patients are reviewed in clinic on a 6 monthly basis by the Consultant. How willing would you be to accompany the patient to a Nurse-Led Clinic, run by Specialist Nurses, in between an annual Consultant appointment?

Very Willing Willing

Unsure Unwilling

Very Unwilling Need to know more before deciding ...

Not applicable

Q16c If "Unwilling" or "Very Unwilling" to attend a Nurse-Lead Clinic, please feel free to comment:

Experience at the Clinic today

Q17 How would you rate your overall experience at the clinic today?

Very Good..... Good..... OK..... Poor..... Very Poor.....

Q18 Please tell us what has been Very Good or Good about your experience today?

Q19 Please tell us what has not been so good?

Q20

What would have made your experience better?

Thank you for completing the questionnaire. Please place it in the box provided. The results of the audit will be analysed by the Clinical Effectiveness team and will be discussed with the multidisciplinary team and will be fed back to our patients at the clinic. If you have any questions raised by completing this questionnaire, please do not hesitate to speak to a member of staff.

Louise Henderson
Specialist Parkinson's Nurse

January 2014

Staff Experience of the Parkinson's Disease Clinic



Thank you for agreeing to complete this questionnaire and provide real time feedback about your experience in Clinic today.

Q1 Clinic:
 Banchory..... Peterhead..... Woodend.....

The Clinic Today:

Q2 You are..?

Consultant.....	<input type="checkbox"/>	Physiotherapist.....	<input type="checkbox"/>
Specialist Parkinson's Nurse.....	<input type="checkbox"/>	Occupational Therapist.....	<input type="checkbox"/>
Registered Nurse/Staff Nurse.....	<input type="checkbox"/>	Auxiliary Nurse.....	<input type="checkbox"/>
Other Doctor (e.g. Registrar).....	<input type="checkbox"/>		

Q3a How many patients did you see?

New Patient..... Review Patients..... Unsure.....

Q3b Did the clinic start on time?

Yes..... No..... Not Sure.....

Q3c Did the clinic run over time?

Yes..... No..... Not Sure.....

Q4 Which staff assisted at the clinic today..?

Consultant.....	<input type="checkbox"/>	Other Doctor (e.g. Registrar).....	<input type="checkbox"/>
Specialist Parkinson's Nurse.....	<input type="checkbox"/>	Physiotherapist.....	<input type="checkbox"/>
Other.....	<input type="checkbox"/>	Occupational Therapist.....	<input type="checkbox"/>

Other staff (please specify)

Q5 The information you provided to patients and carers today was in which format:
(Tick all that apply)

Verbal only.....

Written (booklets/leaflets) only

Both written (information booklets) and verbal

Information on websites that can be accessed.....

Contact details for support (Nurse specialist etc..)

Q6a How many patients did you refer to other health professionals within the clinic today?

No. of patients..... —

Q6b Which health professional(s) did you refer your patients to today:

Consultant	<input type="checkbox"/>	Other Doctor (e.g. Registrar)	<input type="checkbox"/>
Specialist Parkinson's Nurse	<input type="checkbox"/>	Physiotherapist.....	<input type="checkbox"/>
Other	<input type="checkbox"/>	Occupational Therapist.....	<input type="checkbox"/>

Q6c How many patients did you refer to health professionals outwith the clinic today?

No. of patients..... —

Q6d Where additional Multi-disciplinary Team members were not available to be referred to today, do you think it would have been beneficial for the patient to have had access to them?

Yes No.....

Q7a How many patients did you discuss "Non-Motor" symptoms with today?

All.....	<input type="checkbox"/>	None.....	<input type="checkbox"/>
Some	<input type="checkbox"/>	Not sure	<input type="checkbox"/>

Q7b How many patients did you give treatment recommendations to, for "Non-Motor" symptoms (pharmacological and non pharmacological) today?

All.....	<input type="checkbox"/>	Some	<input type="checkbox"/>
None.....	<input type="checkbox"/>	Not Sure	<input type="checkbox"/>

Future Clinic set-up:

Q8a Do you think the current Clinic arrangements are effective for patients?

Yes No..... Unsure.....

Q8b Do you think the current clinic arrangements meet?

The needs of Patients The needs of Carers. Your clinical goals for patients

Q8c Please comment on your responses to 8a and 8b

Questions 9: Consultants/Doctors Only

Q9a If Consultant/Doctor appointments were changed to annual appointments, would you be happy for a qualified and competent Specialist Nurse Prescriber to..... ?

	Yes	No	Need to know more before deciding
See patients in between annual Consultant appointments.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prescribe medication.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adjust medication.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discontinue medication.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q9b Please provide comments if response 'No' or 'Need to know more'?

Experience at the Clinic Today (All Staff):

Q10 In your opinion was the time allocated to each patient?

Too Long..... Just about right Not long enough

Q11 How would you rate your experience at the clinic today?

Very Good..... Good..... OK..... Poor..... Very Poor.....

Q12 Please say what has been 'Very Good' or 'Good' about your experience today?

Q13 Please say what has not been so good?

Q14 What would have made your experience better?

Thank you for completing the questionnaire. Please place it in the box provided. The results of the audit will be analysed by the Clinical Effectiveness Team and will be discussed within our multi-disciplinary team.

Louise Henderson
Specialist Parkinson's Nurse

February 2014

Project Proposal for Increase in Parkinson's Nursing Service & PD Service Redesign

Aberdeenshire Partnership Change Fund
2013-2015

Louise Henderson
Parkinson's Nurse Specialist

Project Context & Rationale

- Change fund bid April 2013.
 - Passed August 2013
- To achieve more integrated MDT working.
- Make specialist services more accessible.
- To bring services in line with:
 - Health-Fit vision. (NHS Grampian, 2010)
 - QIS Standards for Neurological Care. (The Scottish Government, 2010)
 - NICE Guideline 35: Parkinson's Disease Management. (National Institute for Clinical Health and Excellence, 2006)
- Msc. Project undertaken by Louise in September 2013.

Aims of the Project:

- Redesign the current service alongside our shire colleagues 'Healthfit Service 2020' vision (NHS Grampian 2010)
- Investigation of Nurse-led clinics



OBJECTIVES:

1. To relieve pressure on current consultant led clinics and improve access to specialist Parkinson's services by delivering these services nearer to the patient's own home.
2. To reduce waiting times for new patients to be seen, and reduce the waiting times for complex patient reviews (by means of relieving pressures on consultant time and affording the opportunity to develop 'urgent review' clinic slots.
3. To potentially cut down on avoidable acute admissions to hospital.
4. Improve the patient out-patient clinic experience.



1. Improve patient experience

- The Scottish Government (2010) indicates that their intention is to provide health care which is focused on improved patient experience, improved staff experience, and ensure better access to services.
 - How to achieve this:
 - Addressing the emotional needs of the patients (Logan and Hurwitz, 2013)
 - Non-motor symptom management
 - Improvement in opportunities for the patient learning and self-care (Pagels et al. 2008)
 - The opportunity to reflect, the provision of information, empathy with the patient, and attitude towards the patient have a great impact on patients quality of life. Satisfaction rating at nurse led clinic 95%. (McMahon and Thomas, 1998)
- Nurse-led MDT clinic aims to address and provide these within longer clinic time slots.



2. Increase access to services

Reducing Waiting Times

- *Clarke et al. (2008)*, explored the concept of nurse-led clinics within a neurology department (nurse-led clinic for routine review of chronic headaches). And reported a dramatic reduction in waiting times.

Reduce Pressure on Consultant Clinics

- Patients who have complex medical issues, have increased and more timely access to the appropriate specialist. *Amandale (2008)*
 - Advanced Nurse Specialist could carry out routine review appointments.
 - Ensures consultant slots available for new and complex patients



3. Reduce Admissions & Cost-Saving

- *Sands (2006)* suggests 50% reduction in admissions in heart failure patients.
- *McAlister et al. (2004)* suggest patients requiring long-term follow up, who attend a multi-disciplinary clinic, experience reduced mortality and that the admissions which the input was preventing, were 'all cause' in nature (not just those admissions which were PD Related).
- Cost-effectiveness of a nurse-led clinic can be determined by off-setting the cost of the current consultant-led service, in comparison with the cost of a nurse-led MDT clinic. (*Hendriks et al. 2013*)

Nurse-Led Multi-Disciplinary Clinic (Calculated at mid-range Band 7 on pay scale)	Current Service: Consultant & Specialist Nurse (Both calculated at mid-range on pay scale, with Nurse being calculated at Band 6, as per current service)
Advanced Nurse Specialist: £872.16	Consultant: £2116.32
Physiotherapist: £730.08	Parkinson's Specialist Nurse: £730.08
Occupational Therapist: £730.08	Secretarial input: £253.92 (2 hours per month for typing and clinic admin)
Secretarial input: £253.92 (2 hours per month for typing and clinic admin)	
Total: £2586.24	Total: £3100.32
Average Saving per Year: £469.92 (N.B. Saving in Year 1: £149.92 - due to initial overheads)	

• **Note: Direct replacement**

Consultant led-clinic replacement
Vs.
Complementary to consultant-led clinic

1 x 4 hour clinic per month.
12 clinics per year.

Assessment of current services:

Nursing Service *(See hand-out)*

- **SWOT Analysis** (*Pearce 2007*)
 - Identify gaps in knowledge of team
 - Analysis of driving/restraining forces with relation to nurse-led MDT clinic
- **Clinical Service Analysis** (*Daly, Speedy and Jackson, 2004*)
 - Effectiveness
 - Efficiency
 - Equity
 - Access
 - Acceptability
 - Appropriateness

DoME PD Service

(Nutley et al. 2008)

- **Allied Health Professionals (AHP) Onward Referral Audit**
 - Non-MDT Clinics only
 - 'Snap-shot' of referrals to AHP's being made during non-MDT clinics
- **In-Patient Audit**
 - To determine how many patients were admitted whilst awaiting Occupational Therapy & Physio input
- **OPD Clinic Experience Audit**
 - Patients
 - Carers
 - Staff

Allied Health Professionals (AHP) Onward Referral Audit

Aim of this audit:

- **To demonstrate the need for a multi-disciplinary**
 - Documenting the amount of onward referrals to members of the MDT at all clinics.
 - 5 month duration

Clinic Date	Clinic Code	OT Referrals	PT Referrals	SALT Referrals	Dietetics Referrals	Pharmacy Referrals	Psych. Referral	Care Manager Referrals	Other comments
12/07/13	AMQ	0	0	1	1	0	1	0	Ortho-paedics x1
25/07/13	CMB	0	0	0	0	0	0	1	
01/08/13	SBR PET	0	0	0	0	0	0	0	Nil
07/08/13	SICH MDT clinic	7	7	1	0	0	0	0	Day Hospital x1
23/08/13	RCAS	0	0	0	0	0	0	0	Nil
03/10/13	SBR PET	1	1	0	0	0	0	0	Nil
09/10/13	AMQ	0	0	0	0	0	0	0	Nil
07/10/13	RCAS	0	0	0	0	0	0	0	Nil
18/10/13	SBR WGH	0	0	0	0	0	0	0	Nil
17/10/13	SBR PET	0	0	0	0	0	0	0	Continence Service x1
06/11/13	SICH MDT clinic	5	5	0	0	0	0	0	Day Hospital x1
07/11/14	SBR PET	0	0	0	0	2	1	0	
19/11/13	CMB	0	1	0	0	0	0	0	Nil
04/11/13	AMQ	1	0	1	0	0	0	0	Radio-graphy Services x1
15/11/13	SBR	0	0	0	0	0	0	0	Nil
14/11/13	CMB	2	0	1	0	0	0	1	
Total:	-	16	13	4	1	2	2	2	

Evaluation of Parkinson's Care of the Elderly Out Patient Clinic: Perspectives from Patient, Carers and Staff

Out-Patient Clinic Experience Audit

Aims of this Audit

(Flynn 2005)

1. To establish current patient/carer/staff satisfaction ratings.
2. Professionals carer/patient would like to see at clinic.
3. Highlight non-motor symptom assessment.
4. Willingness to attend/support Nurse-led MDT clinic.

- The Healthcare Quality Strategy for NHS Scotland (The Scottish Government, 2010).
- Questionnaires x3 compiled with Clinical Effectiveness.
- Three clinics included in Pilot audit (SICH, SBR-WGH & SBR-PET).
- Carers x 7
- Patients x 12
- Staff x 7

Aims	Patients (12)	Carers (7)	Staff (7)
To establish current patient/carer/staff satisfaction ratings. [Concl. Doing generally well?non-MDT invalid comparison]	(11) 91.7% V. good (1) 8.3% Good	(5) 71.5% Very good (1) 14.25% Good (1) 14.25% Okay	(3) 42.9% V. Good (3) 42.9% Good (1) 14.2% Okay
Professionals carer/patient would like to see at clinic. [Concl. Expectation to see named consultant and PNS; all staff believe MDT clinic beneficial]	(3) Cons. (4) PNS (1) OT (1) Other	(1) Cons. (2) PNS (1) OT	<i>Beneficial to have MDT members at non-MDT clinic?</i> (7) Yes 100%
Who discussed non-motor symptoms. [Concl. Recognition from all that NMS's not being address in all patients]	(5) 50 % Cons. (3) 30% None (1) 10% PT (1) 10% Not sure (2 - no response)	(3) 42.9% Consultant (1) 14.3% PNS (1) 14.3% Doctor (4) 57.1% Nobody (128.9%, some ticked more than 1)	How many patients did you discuss NMS's with? (3) 42.9% All (3) 42.9% Some (1) 14.2% None
Willingness to attend/support Nurse-led MDT clinic. [Concl. Further info needed prior to implementation]	(5) 45.5% V. Willing (4) 36.4% Willing (2) 18.1% Need to know more.	(2) 28.6% V. willing (3) 42.9% Willing (1)14.25% Unsure (1)14.25% Need to know more	(4) Yes to See patients between annual consultant slots, adjust meds, stop meds. (3) Yes to Rx (1) Need to more for Rx

NLC- Nurse Specialist Role

Outline of Leadership Attributes

- Curtis and O'Connell (2011):
- An idealised influence, admired and respected.
 - Transformational nature
 - Intellectually stimulating
 - Motivational
 - Inspirational
 - Considerate of each individual which they intend to lead. (NHS Scotland, 2005, and NHS Grampian, 2009).

Outline of Advanced Clinical Practice & Day-to-Day tasks

- Guidelines and competency level indicators:
- Competency Framework for Nurses working in Parkinson's Disease (Royal Collage of Nursing, 2008)
 - NHS National Nursing Profile (NHS Scotland 2006)
- (See hand-out)

International Council of Nurses (2009) indicate that a general nurse may be able to perform in a specialist role at a lower level of responsibility, but to work at this advanced level, one must first be practicing at a lower level of specialism before progressing to Advanced Specialist Nurse status.

Training & Nurse Development

Training & Nurse Development

- Formal neurological clinical examination
- Medication recommendations
- Time management
- Financial and budgetary awareness
- Inter-disciplinary working

Prescribing

- Complements a specialist role.
- Helps towards a more integrated nursing service.
- Ultimately overcomes difficulties in the health care system which once would have delayed patients' access to medicines. (Bradley and Nolan, 2007)
- Prescribe within their area of speciality, and within their own level of competency (Nursing and Midwifery Council, 2005) (See hand-out)

The practice of nurse prescribing:

- Provides better care for patients
- Faster access to medicines
- Better use of nurses' and doctors' time (The Scottish Government, 2009).

Supporting key health care policy in Scotland including:

- The shift from acute-driven to community-driven services
- Caring for an ageing population with an increase in long term conditions
- Focusing on wellness rather than treating illness
- Address a key theme of patient safety (The Scottish Government, 2009).

Action Plan *(see hand-out)*

FISHER, (1996)

- Calculated at advanced nurse specialist level, in accordance with recommendations outlined earlier.
- Clinic commitment has been outlined as four hours.
 - Administrative duties (i.e. dictating letters, liaising with General Practitioners, social worker and other disciplines).
 - Preparation for the inevitable happening, where a patient may require unplanned intense input, which cannot be provided within the allotted clinic time.
- A band six, senior practitioner has been selected from both Occupational Therapy and Physiotherapy due to the autonomy of the post. Costs calculated using mid-range Band 6 for each, for four hours per clinic, and for 12 clinics over the year.
- Rows 7, 8 and 9: These are anticipated to be one-off overhead costs which will only be incurred within the first year.

Future Developments

- Grampian- wide PD Service re-design?
- Incorporate further nurse led clinics within the region.
- Secure support from our colleagues within the Aberdeenshire clusters.
- Secure further long-term financial support from local, and regional, managers.
- Continued auditing and evaluation of the service: evaluate the impact which this clinic has made.
- Pilot questionnaires to be re-worked: On-going monitoring of patient/carer/staff satisfaction levels.

DISTRIBUTION LIST

Electronic Version of Report and Executive Summary distributed to:

- Helen Robbins, Associate Director of Quality, NHSG
- Quality, Governance and Risk Team Leaders: Brenda Lurie, Liz Tait, Jude Scott, Fiona Mitchelhill
- Clinical Governance Coordinators/Facilitators: Janice Rollo, Alan Cooper, Ashley Allan,
Note: For cross sector circulation to groups/committees within own sectors
- Laura Dodds, Corporate Communications, NHSG, laura.dodds@nhs.net;
- Alison McGruther, Unit Nurse Manager, Woodend Hospital alison.mcgruther@nhs.net;
- June Brown, Associate Director of Nursing, NHS Grampian june.brown@nhs.net;
- Shona Strachan, AHP Lead (Aberdeenshire) shona.strachan@nhs.net;
- Lynn Morrison, AHP Lead (City) lynn.morrison@nhs.net;
- Anne Mackenzie, AHP Lead (Moray) anne.mckenzie@nhs.net;
- Valerie Leslie, Parkinson's Specialist Nurse v.leslie@nhs.net;
- Heidi Simpson, Parkinson's Specialist Nurse heidi.simpson@nhs.net
- Jennie Williams, Area Operations Manager, jenniewilliams@nhs.net;
- Consultant, Medical Staff and AHP's at the clinics (via onward distribution through Parkinson's Specialist Nurses (Woodend)
- Iain Ramsay. Head of Healthcare , Aberdeenshire Health and Social Care Partnership
iainramsay@nhs.net

Robert Gordon University:

- Karen Strickland, Associate Head of School k.strickland@rgu.ac.uk
- Dr Mary Addo, Lecturer m.a.addo@rgu.ac.uk
- Dr Colin Macduff, Reader c.macduff@rgu.ac.uk
- Una Lyon, Lecturer u.lyon@rgu.ac.uk
- Dr Sheelagh Martindale, Head of Professional Development s.martindale@rgu.ac.uk

Electronic Version of Executive Summary published on the Document Management System of NHS Grampian intranet Keywords: 2015, Audit *Evaluation of Parkinson's 'Care of the Elderly' Out-patient Clinics from Patients, Carers and Staff Perspectives* (Care of the Elderly Clinics, Patient, Carer, Staff, Parkinson's)

Executive Summary also available from the Quality, Governance & Risk Unit webpage and listed under 'Most Recently Added' within the 'Clinical Audits Completed' folder Project ID: 2695

Evaluation of Parkinson's Care of the Elderly Out Patient Clinic: Perspectives from Patient, Carers and Staff