Royal College of Occupational Therapists

UK PARKINSON'S Excellence Network

2022 UK Parkinson's Audit

Occupational therapy

Standards & Guidance

2022 UK Parkinson's Audit
Occupational therapy

Audit of national standards relating to Parkinson's care, incorporating the Parkinson's NICE guideline,[1] NICE quality standards[2] and other relevant evidence-based guidelines.

Aim

The aim of the occupational therapy audit is to establish if occupational therapy services are providing quality services for people with Parkinson's, taking into account recommendations made in evidence-based guidelines.

Objectives

1. To encourage occupational therapists to audit compliance of their local Parkinson's service against Parkinson's guidelines, by providing a simple peer reviewed audit tool with the facility for central data analysis to allow benchmarking with other services.
2. To identify areas of good practice and areas for improvement to inform local, regional and UK-wide discussions leading to action plans and quality improvement initiatives to improve quality of care.
3. To establish baseline audit data to allow:
    - UK-wide mapping of variations in quality of care
    - local and UK-wide mapping of progress in service provision and patient care through participation in future audit cycles

Background

The Parkinson's occupational therapy audit is part of the UK Parkinson's audit coordinated by Parkinson's UK and led by a steering group of professionals.

This is the sixth round in which occupational therapists will be able to take part, along with physiotherapists and speech and language therapists. Consultants in elderly care and neurology (and their Parkinson's nurses) can participate in the parallel patient management audit. The occupational therapy audit has received research governance approval by the Royal College of Occupational Therapists. The audit questions for this round have been refined to reflect feedback from the 2019

[1] National Institute of Health and Clinical Excellence. *Parkinson's Disease in Adults NG71.* (2017) Available at https://www.nice.org.uk/guidance/ng71
[2] Nice Quality Standard QS164 https://www.nice.org.uk/guidance/qs164

audit, and the audits have all been reduced in length to encourage the participation of under-pressure services.

Standards

The occupational therapy audit has been structured according to *Occupational therapy for people with Parkinson's: Best Practice Guide*[3] and the National Service Framework for Long Term Conditions[4]. It has also been structured according to principles of occupational therapy for Parkinson's, as outlined by the NICE guideline[5] and Quality Standards.[6]

The principles of occupational therapy for Parkinson's include:

- early intervention to establish rapport, prevent activities and roles being restricted or lost and, where needed, to develop appropriate coping strategies
- client centred assessment and intervention
- development of goals with the individual and carer, with regular review
- employment of a wide range of interventions to address physical and psychosocial problems to enhance participation in everyday activities, such as self care, mobility, domestic and family roles, work and leisure (NICE NG71 2017, quoted in Occupational therapy for people with Parkinson's: Best Practice Guide second edition 2018 p15)

The NICE guideline (2017, p17) states that people who are in the early stages of Parkinson's disease should be referred to an occupational therapist with experience of Parkinson's disease for assessment, education and advice on motor and

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[3] Aragon A, Kings J (2018) *Occupational therapy for people with Parkinson's: 2nd edition. London: RCOT.* Available at http://www.parkinsons.org.uk/sites/default/files/publications/download/english/otparkinsons_guidelines.pdf

[4] Department of Health. *National Service Framework for Long Term Neurological Conditions*. (2005) Available at: www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

[5] National Institute of Health and Care Excellence. Parkinson's Disease in Adults NG71. (2017) Available at https://www.nice.org.uk/guidance/ng71

[6] Quality Statement 3: https://www.nice.org.uk/guidance/qs164/chapter/Quality-statement-3-Referral-to-physiotherapy-occupational-therapy-or-speech-and-language-therapy

non-motor symptoms and to offer Parkinson's disease-specific occupational therapy for people who are having difficulties with activities of daily living.

Methodology

This audit is open to all occupational therapy services and individual occupational therapists that work with people with Parkinson's in the UK, whether hospital or community based, clinic or domiciliary service (excluding acute hospital inpatients).

Standards agreed to be pertinent to occupational therapy have been transformed into a set of audit standards and statements reviewed by specialist occupational therapists. The full list of questions is given in Table 1 (Service audit) and Table 2 (Patient audit) at the end of this document.

Please note the importance of logging your participation in this national clinical audit with your Audit Department.

Patient sample

The minimum audit sample size is 10 consecutive people with idiopathic Parkinson's referred to an occupational therapy service and seen during the audit data collection period, which runs from 1 May 2022 to 30 September 2022.

Take account of the need to capture this minimum sample when deciding locally on your start date for collecting a consecutive patient sample. The data collection tool will have the capacity to capture as many consecutive patients as therapists wish to audit.

The inclusion criteria for audited patients are as follows:

a) Patients who are currently receiving active intervention (including education/counselling) at the start of the audit period.

b) Those who are seen on a review appointment (irrespective of whether they then go to start another episode of active treatment) during the audit period.

c) Patients newly referred to your service who undergo full assessment (again irrespective of whether they then proceed to immediate active intervention rather than being placed on review).

Data entry

Data is entered on an on-line tool; the link is available from www.parkinsons.org.uk/audit.

- The **service audit** section consists of general questions about your service (and needs to be completed only once by a member of the team familiar with the service set-up and running).
- The **patient audit** section allows you to enter data on individual patients. These include both newly seen people with Parkinson's and follow ups, but each person should only be documented once, even if they attend more than once during this period.

Appendix A of this document is a version of the patient questions that you can print and use to record data in your clinics, if this would be useful.

Data entry must be completed by 31 October 2022 when the data will be downloaded for analysis.

'No, but…' answers
A 'No, but…' answer implies there is a pre-determined accepted reason for non-compliance with the standard. The denominator for compliance can then be determined only for those patients where the standard was relevant – ie 'No, but…' answers can be removed from calculations of compliance.

Confidentiality

Patients

Please ensure that any information submitted does not include any personally identifiable information about your patients. Identifiable information is any information you hold about a service user that could identify them. This includes personal details such as names, addresses, pictures, videos or anything else which might identify the service user. Anonymised information is information about a service user that has had all identifiable information removed from it.[7]

When you complete the patient section of the audit, you will see that there is space for a patient identifier. It is suggested that you use code letters or a number here to help you keep track (for example the patient's initials or hospital number) – please

[7] Health Professionals Council. Available at https://www.hcpc-uk.org/registration/meeting-our-standards/guidance-on-confidentiality [accessed 19 January 2022]

do not use NHS numbers. It will help if you keep a list of the code words or numbers securely yourself, so that if there is any query about the information you have submitted, you can track back to the original patient.

Employers
The Healthcare Quality Improvement Partnership (HQIP) recommends that services participating in a national clinical audit should be named in the audit reports. The audit reference report will list all participating organisations. It is therefore vital that you inform your clinical audit department about your participation in the audit.

Participating therapists
Individual therapists who participate and submit data will not be named in the audit report.

Data security

The data collection forms, which will be available online for data entry, will be accessed using a username and password chosen by each user. The password will require a minimum length and complexity according to usual online security methods. Please make sure that your username and password are well protected and can't be accessed by other people. You will be able to indicate that you will work with colleagues on the audit, and you will therefore be able to view entries made by colleagues in your local team. We ask that you comply with your organisation's Data Protection guidelines at all times.

After the data has been accessed by Parkinson's UK it will be stored in password-protected files at Parkinson's UK in accordance with NHS requirements. Within Parkinson's UK, access to the raw data set is restricted to the Clinical Audit Manager, members of the Clinical Steering Group and the Data Scientist who will carry out the data analysis

Raw data will not be accessible in the public domain.

Patient Reported Experience Measure

All services participating in the audit are encouraged to participate in the Patient Reported Experience Measure (PREM). The PREM takes the form of a short paper questionnaire to be distributed to up to 50 consecutive patients between 1 May and 30 September 2022. These patients do not necessarily have to be those included in the main clinical audit.

The questionnaire asks 10 questions about patients' views of their Parkinson's service, and should take only five to 10 minutes to complete. If a carer has accompanied the patient on their clinic visit, they may assist the patient in completion

of the form. Patients should feel comfortable and not overlooked while completing their questionnaire.

No identifiable information is collected, and the patient will seal their completed questionnaire in the envelope provided. These envelopes will then need to be collected before the patient leaves the clinic, and all the envelopes will then be returned to the audit team at Parkinson's UK in the large postage-paid envelope provided.

Each service will be provided with the following resources:

- 50 x copies of a paper questionnaire
- 50 x patient information leaflets
- 50 x sealable envelopes
- A large postage-paid envelope for return of sealed envelopes to the audit team

A minimum of 10 questionnaires will need to be returned for a service's data to be included in the data analysis.

Participating in the PREM will give individual services direct feedback from their service users about the quality of care, accessibility and general satisfaction.

How the audit results will be communicated

The findings of both the clinical audit and the PREM will be presented in the form of a UK-wide summary report and an individual report for each service, benchmarking the results of individual services against the national average for each audit question in their specialty.

The summary report will contain detailed analysis and comments on the data along with key recommendations for commissioners and clinicians. The full data tables will also be available, along with a list of participating services.

A link to the reports will be sent to all audit participants, trust audit contacts and strategic health authority/health board audit contacts. The UK-wide reports will also be in the public domain via the Parkinson's UK website. Individual Service Reports are only accessible within the relevant Trust.

How the data will be used

Data collected during the audit will be used to generate a national picture of service delivery and to compare this with the expectations detailed in national guidance. This data will provide valuable information about priority areas within the existing healthcare provision and will support the development of

commissioning. Information generated through this collaboration will be used in campaigning on behalf of people with Parkinson's, as well as guide the development of UK-wide quality improvement initiatives.

UK Parkinson's Excellence Network

The UK Parkinson's Excellence Network brings together health and social care professionals to transform the care that people with Parkinson's receive across the UK. The Network is there to ensure:

- that everyone with Parkinson's has access to high quality Parkinson's services that meet their needs. Their care should be delivered by an expert, integrated, multi-disciplinary team including a consultant, specialist nurse and range of therapists, whose involvement is key to maximising function and maintaining independence
- there are clear pathways to timely, appropriate information, treatments and services from the point of diagnosis, including access to specialist mental health services, and Parkinson's UK's full range of information and support to allow people to take control of the condition
- services will be involved in continuous quality improvement through audit and engagement of service users in improvement projects.

Thank you for your participation in the 2022 UK Parkinson's Audit

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Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A company limited by guarantee. Registered in England and Wales (948776). Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ. A charity registered in England and Wales (258197) and in Scotland (SC037554)

Occupational therapy - Service Audit

	Question	Data items/answer options	Help notes
Your details			
1.1	Name of Lead Therapist completing the Service Audit	Free text	
1.2	Contact email of Lead Therapist	Free text	
Service Description			
2.1	Describe the setting in which you usually see individuals with Parkinson's	• Integrated medical and therapy Parkinson's clinic • Acute outpatient rehabilitation • Community rehabilitation service • Social services including reablement • Outpatient/day hospital • Individual's home • Other (please specify)	Choose one – the most common setting for the service
2.2	Does your service specialise in the treatment of individuals with neurological conditions?	• Yes • No	
2.3	Does your service specialise in the treatment of individuals with Parkinson's?	• Yes • No	

Individuals with Parkinson's			
3.1	Approximately what percentage of the individuals referred to your service annually have a diagnosis of Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-100%	
Occupational therapy Professionals			
4.1	Within your service, can you access Parkinson's related continuing professional development (at least yearly)?	• Yes • No	Training includes in-service within the Trust/similar body /Board/Local Health Board or external courses
4.2	Are there any documented induction and support strategies for new occupational therapists working with individuals with Parkinson's?	• Yes, specifically in relation to patients with Parkinson's • Yes, as part of more general competencies • No	
4.3	What support (e.g. education, advice) is available to individual therapists working in the service?	• They can consult any member of the Parkinson's specialist MDT as they are a member • They can consult members of a general neurology/elderly care specialist service of which they are a member • They do not work directly in Parkinson's clinics but can readily access a	Choose one

		Parkinson's MDT/Parkinson's Nurse Specialist • They do not work directly in a specialist clinic but can readily access advice from a specialist neurology or elderly care MDT • No support available	
Clinical Practice			
5.1	How does your service approach assessment of an individual with Parkinson's?	• MDT assessment • OT specific assessment • Both	
5.2	How is the assessment undertaken?	• Interview with patient and carer • Assessment during group work • Functional assessment • Standardised assessment	
5.3	How do you usually see your patients with Parkinson's?	• Individually • In a group setting • Both individually and in groups	
5.4	How are patients seen?	• In person • Virtually - by video • Virtually - by telephone	Tick all that apply
5.5	Are outcome measures being used?	• Yes • No	https://www.rcslt.org/wp-content/uploads/media/docs/selecting-outcome-measures.pdf

5.5a	If yes, what type?	• Self report • Clinician administered • Report by family/carer • Service data	Self report includes Patient Reported Outcome Measure (PROM), Patient Reported Experience Measure (PREM), satisfaction measures
5.6	What needs are regularly addressed through your interventions?	• Work roles • Family roles • Domestic activities of daily living • Leisure activities • Transfers and mobility • Personal self care activities such as eating, drinking, washing and dressing • Environmental issues to improve safety and motor function • Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems • Management of fatigue • Education of condition and self-management • Social interaction/social support • Other (please specify)	Tick all that apply
5.7	Where do you carry out the intervention?	• Individual's home • Community setting • Outpatient/day hospital/centre • Hospital	Choose one

Occupational therapy - patient audit

	Question	Data items/answer options	Help notes
1.	**Demographics**		
1.1	Patient identifier	*This can be used by you to identify audited patients*	
1.2	Gender	• Male • Female • Other/patient prefers not to say	

1.3	Ethnicity	• White
		  o British
		  o Irish
		  o Traveller
		  o Any other White background
		• Asian/Asian British
		  o Indian
		  o Pakistani
		  o Bangladeshi
		  o Chinese
		  o Any other Asian background
		• Black/African/Caribbean/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic groups
		  o White and Black Caribbean
		  o White and Black African	

		○ White and Asian ○ Any other mixed background • Other ethnic group ○ Arab ○ Any other ethnic group • prefer not to say	
1.4	Year of birth		
1.5	What setting does this Patient live in?	• Own home • Residential care home • Nursing home • Other (please specify)	
1.6	In what setting was the individual seen?	• NHS – outpatient • NHS - community • Private clinic • At home • Other (please specify)	
1.7	How was this person assessed?	• In person • Virtually - by video • Virtually - by telephone	Tick all that apply
1.8	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative	Definitions of phases **Diagnosis** • From first recognition of symptoms/sign/problem • Diagnosis not established or accepted. **Maintenance** • Established diagnosis of Parkinson's • Reconciled to diagnosis • No drugs or medication 4 or less doses/day • Stable medication for >3/12

			• Absence of postural instability. **Complex** • Drugs – 5 or more doses/day • Any infusion therapy (apomorphine or duodopa) • Dyskinesia • Neuro-surgery considered / DBS in situ • Psychiatric manifestations >mild symptoms of depression/anxiety/hallucinations/psychosis • Autonomic problems – hypotension either drug or non-drug induced • Unstable co-morbidities • Frequent changes to medication (<3/12) • Significant dysphagia or aspiration (for this audit, dysphagia should be considered a prompt for considering end of life issues). **Palliative** • Inability to tolerate adequate dopaminergic therapy • Unsuitable for surgery • Advanced co-morbidity (life threatening or disabling).
2. Referral			
	Standard A: Consider referring people who are in the early stages of Parkinson's disease to an occupational therapist with experience of Parkinson's disease for assessment, education and advice on motor and non-motor symptoms. (NICE 1.7.5) **Standard B: There is timely integrated assessment involving all relevant health agencies leading to individual care plans, which ensure that staff have access to all relevant records and background information about the person's condition, test results and previous consultations.** (NSF QR1)		

	NSF QR1 - An integrated approach to assessment of care and support needs, and to the delivery of services is key to improving the quality of life for people with LTC. The most effective support is provide when local health and socials services team communicate ; have access to up to date case notes and patients held records and work together to provide a co-ordinated service		
2.1	Year of Parkinson's diagnosis		
2.2	Has the person received previous occupational therapy specifically for Parkinson's?	• Yes, please go to Q x.x • No, please skip to Q x • Offered but declined • Unknown	
2.2a	If yes, what was the year of first referral?	(year or unknown)	
2.3	When the person was first referred to any OT service, at what stage of their Parkinson's were they?	• Diagnosis • Maintenance • Complex • Palliative • Unknown	
Current episode of care			
2.4	Who made the referral to OT?	• Elderly care consultant • Neurologist • Parkinson's nurse specialist • General/non-PDNS nurse • GP • Allied health professional colleague (physio/SLT) • Dietician • Social care worker	

		• Self-referral/relative • Other (please specify) • Unknown	
2.5	What was the time between the date of the referral and the date of the initial appointment for this episode of care?	• 1 to 4 weeks • 5 to 8 weeks • 9 to 12 weeks • 13 to 18 weeks • More than 18 weeks	Where are open referral system is operating, this is the current episode of care - i.e. each episode of care is considered a 'new referral'
2.6	Has this referral been triggered as a result of a medical review?	• Yes • No • Unknown	
2.7	What was the reason for referral to OT?	• Work roles • Family roles • Domestic activities of daily living • Leisure activities • Transfers and mobility • Personal self-care activities such as eating, drinking, washing and dressing • Environmental issues to improve safety and motor function • Mental wellbeing, including, cognition, emotional and/or neuro-psychiatric problems • Management of fatigue • Other (please specify)	Tick all that apply

3. Goals identified			
	Standard C: People with Parkinson's disease should have a comprehensive care plan agreed between the person, their family members and carers (as appropriate), and specialist and secondary healthcare providers. (NICE 1.1.5) **Standard D: Development of goals in collaboration with the individual and carer with regular review** (Occupational Therapy for People with Parkinson's: best practice guidelines, College of Occupational Therapists, 2018, p15).		
3.1	Were therapy goals set in collaboration with the patient and/or carer?	• Yes • No	
3.2	Were standardised assessments used with this patient?	• Yes • No	
3.2a	If yes, what areas were you assessing for?	• Activity, function, participation • Cognition • Mood • Fatigue • Goal setting • Health and wellbeing	
4. Intervention strategies used			
	Standard E: Offer Parkinson's disease-specific occupational therapy for people who are having difficulties with activities of daily living. (NICE 1.7.6)		

4.1	Which areas of intervention were addressed?	• Staying well
		• Self management
		• Specific strategies for initiating and maintaining movement – intrinsic or extrinsic cues
		  o Optimising function
		  o Mobility/transfers
		  o ADLs
		  o Fatigue management
		  o Posture
		  o Communication
		• Cognitive and emotional wellbeing
		• Engagement/motivation
		• Equipment provision/environmental adaptation
		• Moving and handling guidance
		• Carer support
		• Onward referrals and support
			Tick all that apply

5. About the Occupational Therapist			
5.1	What band (grade) is the occupational therapist who carried out the initial assessment of this person?	• 4 • 5 • 6 • 7 • 8a • 8b • 8c • Social service grade – junior occupational therapist • Social service grade – senior occupational therapist • Other	

5.2	Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown	
6. Evidence base			
6.1	Which of the following did the audited therapist use to inform clinical practice or guide intervention?	• Clinical experience • Advice from colleague or supervisor • Occupational therapy for people with Parkinson's - best practice guide 2nd edition (2018) • Information from Parkinson's UK website • National Service Framework for Long term Conditions (2005) • NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017) • Progressive Neurological Conditions toolkit 2019 • Allied Health Professionals' competency framework for progressive neurological conditions • Published evidence in a peer reviewed journal • Training courses • Webinars, Social Media • None • Other (please specify)	Tick all that apply

Appendix A: Printable patient audit sheet

Use this to record your patient cases before entering the data on the online tool.

1.	**Demographics**	
1.1	Patient identifier	
1.2	Gender	• Male • Female • Other/patient prefers not to say

1.3	Ethnicity	• White
		  o British,
		  o Irish
		  o Traveller
		  o Any other White background)
		• Asian/Asian British
		  o Indian
		  o Pakistani
		  o Bangladeshi
		  o Chinese
		  o Any other Asian background
		• Black/African/Caribbean/Black British
		  o African
		  o Caribbean
		  o any other Black background
		• Mixed/multiple ethnic groups
		  o White and Black Caribbean
		  o White and Black African
		  o White and Asian
		  o Any other mixed background
		• Other
		  o Arab
		  o Any other ethnic group
		• prefer not to say

1.4	Year of birth	
1.5	What setting does this Patient live in?	• Own home • Residential care home • Nursing home • Other (please specify)
1.6	In what setting was the individual seen?	• NHS – outpatient • NHS - community • Private clinic • At home • Other (please specify)

1.7	How was this person assessed?	• In person • Virtually - by video • Virtually - by telephone
1.8	Parkinson's phase	• Diagnosis • Maintenance • Complex • Palliative
2. Referral		
2.1	Year of Parkinson's diagnosis	
2.2	Has this person received previous occupational therapy specifically for Parkinson's?	• Yes, please go to Q2.2.a • No (skip to Q2.4) • Offered but declined (skip to Q 2.4) • Unknown (skip to Q2.4)
2.2a	If yes, what was the year of first referral?	
2.3	When the person was first referred to any OT service, at what stage of their Parkinson's were they?	• Diagnosis • Maintenance • Complex • Palliative • Unknown
Current episode of care		
2.4	Who made the referral to OT? (pick one)	• Elderly care consultant • Neurologist • Parkinson's nurse specialist • General/non-PDNS nurse • GP • Allied health professional colleague (physio/SLT) • Dietician • Social care worker • Self-referral/relative • Other (please specify) • Unknown
2.5	What was the time between the date of the referral and the date of the initial appointment for this episode of care?	• 1 to 4 weeks • 5 to 8 weeks • 9 to 12 weeks • 13 to 18 weeks • More than 18 weeks

2.6	Has this referral been triggered as a result of a medical review?	• Yes • No • Unknown
2.7	What was the reason for referral to OT? (tick all that apply)	• Work roles • Family roles • Domestic activities of daily living • Leisure activities • Transfers and mobility • Personal self-care activities such as eating, drinking, washing and dressing • Environmental issues to improve safety and motor function • Mental wellbeing, including cognition, emotional and/or neuro-psychiatric problems • Management of fatigue • Other (please specify)
3. Goals identified		
3.1	Were therapy goals set in collaboration with the patient and/or carer?	• Yes • No
3.2	Were standardised assessments used with this patient?	• Yes • No
3.2a	If yes, what areas were you assessing for?	• Activity, function, participation • Cognition • Mood • Fatigue • Goal setting • Health and wellbeing
4. Intervention strategies used		

4.1	Which areas of intervention were addressed	• Staying well
		• Self management
		• Specific strategies for initiating and maintaining movement - intrinsic or extrinsic cues
		  o Optimising function
		  o Mobility/transfers
		  o ADLs
		  o Fatigue management
		  o Posture
		  o Communication
		• Cognitive and emotional wellbeing
		• Engagement/motivation

		• Equipment provision/environmental adaptation • Moving and handling guidance • Carer support • Onward referrals and support
5. About the Occupational Therapist		
5.1	What band (grade) is the occupational therapist who carried out the initial assessment of this person?	• 4 • 5 • 6 • 7 • 8a • 8b • 8c • Social service grade – junior occupational therapist • Social service grade – senior occupational therapist • Other
5.2	Approximately what percentage of people seen by the audited therapist in a year have Parkinson's?	• 0-19% • 20-39% • 40-59% • 60-79% • 80-99% • 100% • Unknown
6. Evidence base		
6.1	Which of the following did the audited therapist use to inform clinical practice or guide intervention? (tick all that apply)	• Clinical experience • Advice from colleague or supervisor • Occupational therapy for people with Parkinson's - best practice guide 2nd edition (2018) • Information from Parkinson's UK website • National Service Framework for Long term Conditions (2005) • NICE - Parkinson's disease: diagnosis and management in primary and secondary care (2017) • Progressive Neurological Conditions toolkit 2019 • Allied Health Professionals competency framework for progressive neurological conditions • Published evidence in a peer reviewed journal • Training courses • Webinars, Social Media • None • Other (please specify)