Long COVID Rehabilitation Services

Therapy Outcome Measure-- Draft Adapted Scale

Rehabilitation Needs-- Post Covid

A recent study identified no discernible difference between the rehabilitation needs of patients with covid-19 and those admitted to intensive care with other critical illnesses (1). The paper highlights the inequality of access for patients with and without covid-19 and the authors suggest that heightened awareness of healthcare staff and the wider public may contribute to better rehabilitation services for patients with covid-19 (2).

The symptoms can include long term physical impairments such as muscle weakness, weight loss, breathlessness; cognitive impairment such as problems with memory, attention, and executive function; and psychological symptoms such as depression and anxiety(3). Additionally, it is becoming clear that many individuals who have had Covid-19 but who have not required hospitalisation are experiencing similar symptoms.

Introduction to Therapy Outcome Measure

The Therapy Outcome Measures for Rehabilitation Professionals (TOM) (4,5,6) was designed to be a simple, reliable, cross-disciplinary and cross-client group method of gathering psychometrically robust information on a broad spectrum of issues associated with therapy/rehabilitation. The TOMs is based on analysing the goals of rehabilitation which cover: improving the disorder, reducing dependence, improving social participation and having an impact on the well-being of the individual and carer. It allows the AHP, nurses and other health and social care professionals to describe the relative abilities of an individual across these four dimensions and demonstrate change over time. It incorporates the dimensions used by the World Health Organisations International Classification of Disability and Function (WHO ICF 2001). The dimensions include impairment, activity, participation and a dimension not included in the ICF-- that of the well-being of the client and carer (if the carer is involved in the therapy program).

Based on

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Procedure

The procedure for using the TOM requires the health /social care professional to assess the individual referred for treatment using their usual clinical assessment procedures, such as taking the case history, using any standardised tests, observation, report, and consideration of social history. Thus, no additional work/assessments or tests are required. It usually takes less than 2 minutes to assign the appropriate rating. The objective is to reliably summarise the clinical opinion of the relevant professional.

A. Step One

Identify which impairments the patient is suffering from and choose the appropriate TOM Impairment Scale:

Complex Physical Impairment—Page 3

Cardiac Impairment--- Page 5

Cognitive Impairment—Page 6

Psychological Impairment—Page 7

Swallowing Impairment—Page 8

Voice Impairment/ Dysphonia -- Page 10

Respiratory Impairment—Page 11

Chronic Fatigue—Page12

If other impairments are identified-please see list of additional scales on page 18 of this document (available in TOM User Guide).

B. **Step Two** Identify the level of Impairment and Activity restriction using the scales below. Remember that the scales are ordinal and half points can be used to indicate if a patient is slightly better or worse than a descriptor

If other impairments are identified-please see list of additional scales page 18 (available in TOM User Guide).

- C. **Step Three** Use the participation and well-being scales to identify the status of the patient in these 2 domains.
- D. **Step Four** Use the well-being scale for the patient and the carer/family member if appropriate.

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LONG COVID Rehabilitation

To be completed at beginning and end of rehabilitation treatment/episode of care -- can be completed more frequently if required.

Advisable for individuals to be familiar with The Therapy Outcome Measure (5)

Identify descriptor that is 'best fit'. The patient/client/student does not have to have each feature mentioned. Use 0.5 to indicate if patient/client/student is slightly better or worse than a descriptor and as appropriate to age.

NB you may wish to complete Impairment Scale twice i.e. at the worst point of Covid experience and when client is first seen by the Long Covid Rehabilitation Team

Complex Physical Impairment

Identify descriptor that is 'best fit'. The patient/client/student does not have to have each feature mentioned. Use 0.5 to indicate if patient/client/student is slightly better or worse than a descriptor and as appropriate to age.

Impairment

- **0 Profound**. No active movement, severe abnormality of muscle tone and patterns of movement. May have abnormal sensory loss, severe fixed deformities, severe respiratory difficulties. Presence of pathological reflexes.
- **1 Grossly abnormal muscle tone**, occasionally some voluntary movement towards stimulus, some contractures, some pathological reflexes, sensory impairment, severely restricted range of movement, frequent respiratory difficulties.
- **2** Altered muscle tone, some controlled purposeful active movement. Occasional abnormal primitive reflexes. Some joint contractures/fixed limitations, may have sensory impairment.
- **3 Some useful strength**, but abnormal muscle tone, coordinates movement but without accuracy, requires large stable base and low centre of gravity, moderate sensory impairment. Primitive reflexes on pain or noise.
- 4 Slight abnormality of strength, muscle tone, range of movement; minimal involuntary movements. Slightly impaired neurology with mild weakness or incoordination.

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5 Age-appropriate tone, strength, range of movement, co-ordination and sensation.

Activity

- **0 No purposeful active movement**, totally dependent, requires full physical care and constant vigilant supervision. May have totally disruptive and uncooperative behaviour. Dependent on skilled assistance.
- **1 Bed/chair bound but unable to sit independently.** Some very limited purposeful activity. Needs high level of assistance in most tasks. Some awareness, some effort and recognition to contribute to care. Dependent on skilled assistance. **2 Head and trunk control**. Limited self-help skills. Initiates some aspects of ADL. Transfers with one, mobilizes with two. Requires physical and verbal prompting and supervision for most tasks and movements. Participating in care and engaging in some structured activity. Dependent on familiar assistance.
- **2 Altered muscle tone**, some controlled purposeful active movement. Occasional abnormal primitive reflexes. Some joint contractures/fixed limitations
- **3** Transfers or walking requires supervision or help of one. Undertakes personal care in modified supported environment. Appropriately initiating activities and needs assistance or supervision with some unfamiliar or complex tasks. Initiates activities appropriately.
- 4 Carries out personal care and tasks but is less efficient, requires extra time or may need encouragement. Uses memory prompts or other aids effectively. Minimal or occasional assistance required for some complex or unfamiliar tasks.
- 5 Age-appropriate independence.

Don't forget to rate participation and well-being--- see page 14

Cardiac Impairment

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Impairment

- **OProfound**. Severe uncontrolled angina, uncontrolled cardiac failure.
- **1Some control of cardiac function** with multiple drug therapy.
- **2 Cardiac function and angina mostly controlled** with regular medication, at times not controlled.
- 3 Cardiac function and angina controlled well with regular medication.
- 4 Cardiac function and angina controlled with occasional or minimal medication.
- 5 Normal cardiac function.

Activity

- 0 Lacks functional ability. Totally dependent due to severe chest pain/breathlessness/ weakness/dizziness on minimal exertion, i.e., when being transferred bed to chair (room bound).
- 1 Very limited functional ability. Chest pain/breathlessness/weakness/dizziness limiting activities of daily living, i.e., washing, dressing, mobilizing to toilet (house bound). Constant severe fatigue.
- **2** Function limited by chest pain/breathlessness/weakness/dizziness, for example, walking on level ground (50 yards) or one flight of stairs (house/immediate environment bound). Becomes fatigued easily.
- **3 Moderate functional ability**. Chest pain/breathlessness/weakness/dizziness on moderate exertion, i.e., one minute each stage of 10-stage exercise circuit (local environment). Periods of fatigue.
- 4 Mild effect on functional ability. Some occasional reduction in complex or demanding tasks due to pain/breathlessness. Rarely fatigued.
- **5** No functional disability. Able to tackle normal activities.

Don't forget to rate participation and well-being--- see page 14

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Cognitive Impairment

Identify descriptor that is 'best fit'. The patient/client/student does not have to have each feature mentioned. Use 0.5 to indicate if patient/client/student is slightly better or worse than a descriptor and as appropriate to age.

Impairment

- **O Profound**. Unresponsive to all stimuli. Does not recognize people, unable to learn, poor memory responses.
- **1 Non-purposeful random or fragmented responses**. Occasionally responds to some simple commands; may respond to discomfort; responses may be severely delayed or inappropriate. Recognizes some familiar people and routine tasks in context. Cooperates occasionally, attempts to learn simplest routines with maximal assistance.
- **2** Inconsistent reaction directly related to type of stimulus presented. Occasionally responds appropriately. Can attend but is highly distractible and unable to focus on a particular task. Memory is severely impaired; may perform previously-learned task with structure.
- **3** Recognizes familiar people and tasks in most contexts, able to retain small amounts of information consistently. Responds appropriately with some consistency, appears oriented to setting, but insight, judgement and problem solving poor. Memory variable sometimes good, able to cooperate with/learn more complex task.
- 4 Alert and able to learn but needs occasional prompts and assistance, responds well in most situations. Able to recall and integrate past and recent events; shows carryover for new learning and needs no supervision when activities are learned, but has highlevel difficulties, for example abstract reasoning, tolerance for stress, or judgement in unusual circumstances.
- **5 No cognitive impairment**. Responds appropriately, is alert and able to learn.

Activity

- **0** Inability to recognize body functions and requirements. May have totally disruptive and uncooperative behaviour. Totally dependent, requires full physical care and constant vigilant supervision.
- 1 Recognizes bodily requirements and occasionally initiates activity but requires a high level of assistance in most tasks.

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- **2 Able to self-care and relate to others in protected environment** but is dependent on constant verbal/physical prompting and direction. Skilled assistance required.
- **3 Needs occasional verbal prompting** to initiate activity. Able to operate without supervision for short periods. Able to have some independence with encouragement, independent in familiar surroundings only. General supervision required.
- **4 Able to live independently with some occasional support**, requires extra time, encouragement. Assistance required with unfamiliar tasks.
- 5 Age-appropriate independence.

Don't forget to rate participation and well-being--- see page 14

Psychological Condition (anxiety/stress/depression)

Impairment

- **0.Profound**. Continual demonstration of global severe symptoms of stress and anxiety with no relief.
 - **1.Severe anxiety/stress symptoms** demonstrated most of the time but occasionally, in some situations, partial relief is occasionally experienced.
 - **2.Regular high level of anxiety/stress** or moderate anxiety/stress frequently experienced but very occasional periods when stress and anxiety are not a problem.
 - **3.Anxiety/stress regularly experienced** but responds well to support and encouragement.
 - **4.Anxiety/stress levels easily aroused** but copes when strategies/support in place, very occasional difficulties.
 - 5. Normal response in stressful situations.

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Activity

- **O Physically dependent for all functional tasks**. No self-care skills
- **1 Dependent for most tasks but will cooperate**. Physical assistance, encouragement and support required frequently. Carer undertakes burden of tasks.
- 2 Needs verbal and physical prompts/encouragement to initiate most tasks.
- **3 Some physical/verbal support** and encouragement to complete some tasks but initiates appropriately.
- **4 Occasional verbal encouragement needed** and support or extra time required for specific tasks.
- 5 Independent in all areas.

Don't forget to rate participation and well-being--- see page 14

Swallowing Impairment

Dysphagia

Impairment

- **O Profound** Aphagia: Not safe to swallow due to cognitive status/no bolus control/aspiration/absence of oral/pharyngeal swallow. Aspiration risk identified on all consistencies with clinical signs of aspiration. No effective cough reflex. Not able to manage oral secretions. May need regular suction.
- 1 Severe dysphagia Weak oral movements/no bolus control/inadequate/inconsistent swallow reflex. High and constant risk of aspiration on some but not all consistencies or daily. Can occasionally manage oral secretions
- **2 Severe/moderate dysphagia** Cough/swallow reflexes evident but abnormal or delayed. Uncoordinated oral movements. At regular risk of aspiration (several times a week). Difficulty managing oral secretions in some positions or at some times of the day.

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- **Moderate dysphagia** Swallow and cough reflex present. May have poor oral control. At occasional risk of aspiration. Occasional difficulty with managing oral secretions.
- 4 Mild oral/pharyngeal dysphagia. Incoordination but no clinical risk or evidence of aspiration. No difficulty with managing oral secretions.
- 5 No evidence of dysphagia

Activity

- **O** Unable to safely take any fluid/diet/modified consistencies. Unable to manage oral secretions. Needs experienced and constant surveillance. Requires nonoral methods to meet all hydration and nutritional needs. This may or may not be advised to be in the patient's interests by the responsible clinician and multidisciplinary team.
- 1 Oral intake insufficient to meet hydration and nutritional needs. Requires nonoral methods to meet all hydration and nutritional needs feeding or supplements. Occasionally able to take small amounts of food or drink/modified consistencies using compensatory strategies. Constantly refuses oral intake or holds bolus in the mouth. Requires experienced assistance, prompting and supervision. Requires non-oral methods to meet all hydration and nutritional needs. This may or may not be advised to be in the patient's interests by the responsible clinician and multidisciplinary team.
- **2** Additional non-oral nutrition, hydration or supplements needed. Consistently able to take small amounts of small amounts of food or drink/modified consistencies using compensatory strategies. Frequently refuses oral intake or holds bolus in the mouth. Needs experienced assistance, prompting and supervision.
- **3 Oral intake sufficient to meet hydration and nutrition needs** but may require supplements. Consistently able to take modified consistencies using compensatory strategies. May occasionally refuse oral intake but responds to encouragement. Needs some supervision/encouragement. May eat extremely slowly.
- 4 Although eating and drinking is abnormal, it is good enough to meet nutritional requirements No assistance/supervision required. No alternative or supplement feeding required. May take extra time and avoid certain foods, drinks, or eating situations.
- 5 5 Functionally eating and drinking a normal diet.

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Voice Impairment -- Dysphonia

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Impairment

- **O Profound**. Severe persistent aphonia. Unable or does not phonate.
- **1 Severe consistent dysphonia**. Occasional phonation. May be dysphonic with aphonic episodes.
- 2 Moderate dysphonia. Can phonate but frequent episodes of marked vocal impairment.
- **3 Moderate/mild dysphonia**. Less frequent episodes of dysphonia, for example occurs some time each day/or slight persistent 'huskiness'.
- **4 Mild dysphonia**. Occasional episodes of dysphonia occurring, for example on a weekly basis or less.
- **5** No dysphonia. Appropriate/modal voice consistently used.

Activity

- **OVoice production is completely ineffective**/inappropriate in all situations.
- **1 Voice production is completely ineffective**/inappropriate in most situations except occasionally with familiar listeners or modified environments.
- **2 Voice production is effective**/appropriate in modified environments only, for example quiet or familiar situations.
- **3 Voice production is effective**/appropriate but can be unpredictable in some situations. Voice production requires less personal attention and effort in most situations.
- **4Voice production is effective**/appropriate on most occasions. Rarely effortful. Very occasional difficulties experienced.

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5Voice production is spontaneously effective and appropriate

Don't forget to rate participation and well-being--- see page 14

Respiratory Impairment

Identify descriptor that is 'best fit'. The patient/client/student does not have to have each feature mentioned. Use 0.5 to indicate if patient/client/student is slightly better or worse than a descriptor and as appropriate to age.

Impairment

- **O Profound**. Full ventilatory support.
- **1 Some ventilatory support required**, for example, at night. Retains secretions/airway obstruction or altered air blood gases.
- **2** Requires regular oxygen therapy/medication. Altered use of respiratory muscles. Help required to clear secretions. Altered air blood gases.
- **3** Lung function maintained with regular medication. Frequently normal air blood gases. Frequent productive cough, occasional problem with self-clearing of secretions.
- 4 Normal lung function maintained with minimum medication. Non-problematic selfclearing of secretions. Normal air blood gases.
- **5 Normal lung function**. No functional disability, able to tackle exertion appropriate to age without respiratory distress.

Activity

- **0 Unable to move**, breathlessness at rest. Total care required (room-bound).
- **1 Severe breathlessness on movement in bed**, severe orthopnea, breathlessness affecting fluency of speech, requires maximal help in all activities (house-bound).
- **2 Severe breathlessness on minimal exertion**, i.e., transfer from bed to chair, any effort affects speech. Can undertake a few ADL tasks unaided (house/immediate environment-bound).
- **3** Breathlessness walking on level ground (50 yards). Normal speech when undertaking light activity. Independent for limited activities (access to local environment).

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- **4 Breathlessness on flight of stairs**, not breathless on level ground. Occasional reduction in complex or demanding tasks due to pain/breathlessness.
- **5 No functional disability**, able to tackle exertion appropriate to age without respiratory distress.

Don't forget to rate participation and well-being--- see page 14

Chronic Fatigue

Identify descriptor that is 'best fit'. The patient/client/student does not have to have each feature mentioned. Use 0.5 to indicate if patient/client/student is slightly better or worse than a descriptor and as appropriate to age.

Impairment

- **O** Most severe: Persistent severe fatigue, malaise, pain and other symptoms to the extent that the patient requires assistance with all self-care tasks, difficulty mobilizing within the bed to turn over or sit up, and may require assistance with feeding. Difficulty tolerating environmental stimuli such as light, noise, touch, requires masks/ear plugs, etc., or difficulty accepting personal care. Has difficulty with sustaining any minimum communication or cognitive tasks. Concerns about joint mobility and skin integrity due to restricted movement.
- 1 Severe fatigue, malaise, pain and other symptoms to the extent that the patient is unable to mobilize or carry out any daily task for themselves and are bedbound the majority of the time. Frequent difficulty tolerating environmental stimuli such as light or noise, requiring significant modification to the environment. Significant cognitive impairment affecting speech and any mental tasks.
- **2 Severe to moderate** fatigue, malaise, pain, sleep impairment and other symptoms to the extent that the patient has reduced mobility which impacts on their ability to leave their home. Frequently requiring assistance, encouragement and reminders related to activities of daily living, including cognitive tasks.
- **3** Moderate, frequent and fluctuating fatigue, malaise, pain, sleep impairment and other symptoms which worsen after usual daily tasks. Symptoms limit ability to leave the home on occasions. Significant difficulty with memory, word finding and sustaining attention frequently.

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- **4 Mild fatigue**, episodes periods of malaise, pain, sleep impairment and other symptoms. Experiences post-exertional malaise when trying to sustain tasks over and above usual daily tasks. Rarely has difficulty with mobility and self-care. Occasionally reports difficulty sustaining cognitive tasks such as word finding, attention and short-term memory when symptoms worsen.
- **5 No impairment**: Able to undertake age-appropriate personal, occupational and social activity required without being limited by post-exertional malaise.

Activity

NB: Level of activity that is sustainable from day to day.

- **O Minimal active movement**, totally dependent on assistance for all personal care tasks. Confined to bed and unable to sit up/turn over independently. Interaction with the environment, communication tools and others is severely limited.
- **1 Stays in bed majority of the time** but assists or cooperates with caregiver on personal care tasks. Limited purposeful activity and is able to sit up for short periods/roll and turn. Needs assistance with most activities of daily living and transfers. Some awareness and ability to interact and communicate with others.
- **2** Mobilizes within a familiar indoor environment with support/supervision. Able to initiate some aspects of activities of daily living including self-care tasks. Has some self-management skills and is able to complete some valued activities such as listening to music, reading, electronic communication, cards, etc. May require support with cognitive tasks.
- **3 Independent in mobility with limitations**. Can undertake most activities of daily living independently but requires regular rest periods. Able to plan and carry out a range of day-to-day tasks. Able to complete more complex or demanding tasks with assistance and verbal prompting for shorter periods than usual. Tolerates interaction with others for a limited period.
- **4 Independently mobile in familiar environments**. Independent in all activities of daily living. Needs occasional assistance or extra time to complete demanding physical or complex cognitive tasks. Occasionally requires rest after activity more than is usual for someone without the condition. Adapts activity in response to fluctuations in symptoms and uses self-management techniques.
- 5 Independent and able to function.

Don't forget to rate participation and well-being--- see page 14

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Participation and Well-Being scales

These should be used to reflect the status of all patients at each point of data collection-- collect well-being status of both client and carer/family member if appropriate

Participation

(Social participation is defined as a person's involvement /autonomy in activities that provide interaction with others in the society or the community and expresses interpersonal interactions outside the home e.g. education, work, recreation).

- **0** Unable to fulfil any meaningful and/or purposeful role. Unable to participate in any decision making. No social integration. No future plans in place and unable to take part in decision making about the future.
- 1 Requires full, skilled assistance to participate in any purposeful and/or meaningful role. Contributes to some basic and limited decision making. Unable to initiate social integration, low self-confidence/poor self-esteem and socially withdrawn. Can make simple choices but unable to contribute to complex future planning.
- **2 Some participation** in familiar purposeful or meaningful roles. Able to engage more readily in some limited social integration. Able to respond to some social integration and some self-confidence but requires support (physical and/or emotional). Able to express preferences spontaneously for future care but requires support to weigh up options, plan and implement.
- **3** Able to participate appropriately in purposeful and meaningful roles. Able to make some decisions and understands potential consequences. Able to seek out and respond to social integration of their own choice but may need encouragement and/or emotional support. Some self-confidence, and able to contribute to future planning.
- **4 Occasional difficulty** in fulfilling purposeful or meaningful roles. Able to seek out and respond to social integration of their choice. Minor restrictions in some situations but mostly confident; participates in all appropriate decisions and future planning.

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5 Able to fulfil purposeful and meaningful roles. Autonomous decision making and social integration. Support in future planning for complex issues only.

Wellbeing/Distress (to be completed for and with client, and carer if relevant)

- **0** Severe/Constant upset/frustration/anger/distress/embarrassment/concern/withdrawal. High and constant levels of concern/anger/severe depression/apathy. Unable to express or control emotions appropriately.
- **1 Frequently/severe**: Upset/frustration/anger/distress/embarrassment/concern/withdrawal. Moderate concern, becomes concerned easily, requires constant reassurance/support, needs clear/tight limits and structure, loses emotional control easily.
- **2 Moderate/consistent**: Upset/frustration/anger/distress/embarrassment/concern/withdrawal. Concern in unfamiliar situation, frequent emotional encouragement and support required.
- **3 Moderate/frequent**: Upset/frustration/anger/distress/embarrassment/concern/withdrawal. Controls emotions with assistance, emotionally dependent on some occasions, vulnerable to change in routine, etc., spontaneously uses methods to assist emotional control.
- **4** Mild/occasional: Upset/frustration/anger/distress/embarrassment/concern/withdrawal. Able to control feelings in most situations, generally well adjusted/stable (most of the time/most situations), occasional emotional support/encouragement needed.
- **5 Not/inappropriate**: Upset/frustration/anger/distress/embarrassment/concern/withdrawal.

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Patient Reported Experience Measure---PREM

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List of Therapy Outcome Measure adapted scales available in user guide

- Anorexia Nervosa and Bulimia Nervosa-scale under development
- 2. Augmentative and Alternative Communication (AAC)
- 3. Autistic Spectrum Disorder
- 4. Cardiac Rehabilitation
- 5. Cerebral Palsy
- 6. Child Language Impairment
- 7. Challenging Behaviour and Forensic Mental Health
- 8. Chronic Pain
- 9. Cleft Lip and Palate
- 10. Cognition
- 11. Complex and Multiple Difficulty
- 12. Dementia
- 13. Diabetes
- 14. Dietetic Intervention for the Prevention of Cardiovascular Disease
- 15. Dietetic intervention for Enteral Feeding Paediatrics

Dietetic intervention for Home Enteral Feeding – Adult

- 17. Dietetic intervention for Irritable Bowel Syndrome
- 18. Dietetic intervention for Obesity Paediatric
- 19. Dietetic intervention for Obesity Adult
- 20. Dietetic intervention for Undernutrition Paediatrics
- 21. Dietetic intervention for Undernutrition Adults
- 22. Dysarthria

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- 23. Dysfluency
- 24. Dysphagia
- 25. Dysphasia
- 26. Dysphonia
- 27. Dyspraxia Developmental Co-Ordination Difficulties
- 28. Equipment Services
- 29. Head Injury
- 30. Hearing Therapy/ Aural Rehabilitation
- 31. Incontinence
- 32. Laryngectomy
- 33. Learning Disability Communication
- 34. Mental Health
- 35. Mental Health Anxiety
- 36. Multi-Factorial Conditions
- 37. Musculo-Skeletal
- 38. Neurological Disorders (Inc Progressive Neuro Disorders)
- 39. Palliative Care
- 40. Phonological Disorder
- 41. Podiatric Conditions scale under development
- 42. Post Natal Depression
- 43. Respiratory Care- (COPD)
- 44. Schizophrenia
- 45. Stroke
- 46. Tracheostomy
- 47. Wound Care

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- ADHD
- Selective Mutism
- Erratum for AAC
- Acquired Apraxia
- Paediatric Dysphagia
- Sensory Processing Disorder
- Paediatric Podiatry
- Chronic Fatigue Syndrome/ME
- Selective Mutism
- Prefeeding/ parent infant engagement
- Oral Hygiene
- Oral Aversion
- Orthopaedic -Hip and knee surgery
- Transgender Communication
- Trismus
- Cognitive Impairment-- Communication Disorder
- Velopharyngeal Dysfunction
- Vocal Tract Discomfort
- Auditory impairment /deafness/ partially hearing
- Acute Enteral Feeding

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