# Centre ID\_\_\_\_SMAREACH No:\_SN\_\_\_\_\_\_\_\_\_Pt ID\_\_\_\_\_Date \_ \_ / \_ \_ \_ / \_ \_ \_ \_ Assessor\_\_\_\_\_\_\_\_\_\_\_\_Signature\_\_\_\_\_\_\_\_\_\_\_\_

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|  |
| --- |
| Functional Scale Worksheets |
| Core Worksheets Version 5.8  For use in  SMA-REACH UK- IRAS 122521 study  13th July 2021 |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Time of appointment**  **\_ \_ : \_ \_ (24 hr)** | **Scale Total score** | **Completed**  **Y / N** | **Reason not completed (code)** | **Mode of Assessment** | **Score** | **Out of** |
| ALL | Vignos |  |  |  |  | 10 (reversed) |
| ALL | Brooke |  |  |  |  | 6 |
| ALL (MAA\*) | **WHO\*** |  |  |  |  | 6 |
| Non-ambulant (MAA\*) | **HINE\*** |  |  |  |  | 26 |
| ALL if able to get on plinth (MAA\*) | **RHS\*** |  |  |  |  | 69 |
| As RHS | HFMSE |  |  |  |  | 66 |
| Non-ambulant predominantly (MAA\*) | **RULM\*** |  |  |  |  | 37 (exclude Item A – entry in total) |
| Infants (MAA\*) | **CHOP-INTEND\*** |  |  |  |  | 64 |
| Ambulant | 6MWT – distance |  |  |  |  | metres |
| Non-ambulant - older | EK2 |  |  |  |  | 51 (reversed) |
| ALL (MAA\*) | **CONTRACTURES\*** |  |  |  | ------------ | (See additional info) |
| Respiratory measures | FVC / PCF |  |  |  |  | NA |

**MODE OF ASSESSMENT: F2F = F/ Phone Consultation= P/ Video Consultation= VC/ Recorded Videos = RV**

**Reasons not completed coding (for whole scale or parts of a scale):**

|  |  |
| --- | --- |
| D | Disease progression reason unable (e.g. non-ambulant?) - will stay this way in NH |
| T | Temporary reason unable (e.g. acute injury, fracture, vomiting) - may change in future |
| E | Evaluator error (forgot, wrong test) - cannot be assumed as a 0 |
| P | Patient error, could be behaviour / refusal - cannot be assumed as a 0 |
| N | Other (Specify) **1.**too young/too old **2.**Not understanding instructions **3.**fatigue/pain **4.** Space/equipment **5**.Time issue **6**.Service limitation **7.**Telephone/Video so not able (but superseded by COVID) **8.**other |
| C | Covid-19 related reason |

Assessor Initials\_\_\_\_\_\_\_\_\_\_\_\_

**Hammersmith Infant Neurological Examination**

| (Adapted May 2021 by Anna Mayhew to improve measurability and provide linkage with WHO MM and RHS)  Complete with subjects less than/equal to 2 years old | | | | | | |
| --- | --- | --- | --- | --- | --- | --- |
| **Motor Function** | **Milestone Progression Score – may perform in any observed order** | | | | | **Score** |
| 0 | **1** | **2** | **3** | **4** |
| **Voluntary Grasp** | No grasp | Uses whole hand | Index finger and thumb but immature grasp | Pincer grasp  (thumb and index finger only) |  |  |
| **Ability to Kick (in supine)** | No kicking | Kicks horizontal; legs do not lift | Upward (vertical) | Touches leg | Touches toes |  |
| **Head control** | Unable to maintain upright | Wobbles | All the time upright  (At least 30 seconds) |  |  |  |
| **Rolling** | No rolling | Rolling to side  (Perpendicular pelvis and shoulders to mat. At least to one side) | Prone to supine  (At least in one direction) | Supine to prone  (At least in one direction) |  |  |
| **Sitting** | Cannot sit | Sits with support at hips | Props | Stable sit  (No arms support and for 10 seconds) | Pivots (rotates)  (At least 30° pelvis pivot – moves legs) |  |
| **Crawling** | Does not lift head | On elbow  (Maintain head up for at least 3 seconds) | On outstretched hand  (Maintain head up for at least 3 seconds) | Crawling flat on abdomen | On hands and knees  (At least 3 continuous, consecutive movements in a row) |  |
| **Standing** | Does not support weight | Supports weight | Stands with support  (At least 10 seconds supported standing, hands only -no leaning trunk) | Stands unaided  (At least 10 seconds) |  |  |
| **Walking** | No walking | Bouncing | Cruising (holding on)  (At least 5 steps) | Walking independently  (At least 5 steady steps) |  |  |
| **Total Score out of 26** |  | | | | | /26 |

**WHO Motor Milestones – current achievement**

|  |  |
| --- | --- |
| **\*WHO DEVELOPMENTAL MILESTONES** | **Qualifier met:** |
| **W1. Sitting without support:**  Child sits upright with head erect for at least 10 seconds. Child does not use arms or hands to balance body or support position. | Y  N  |
| **W2. Hands and knees crawling:**  Child alternately moves forward or backward on hands and knees. The stomach does not touch the supporting surface. There are continuous and consecutive movement, at least 3 in a row. | Y  N  |
| **W3. Standing with Assistance:**  Child stands in upright position on both feet, holding onto a stable object (e.g. furniture) with both hands without leaning on it. The body does not touch the stable object, and the legs support most of the body weight. Child thus stands with assistance for at least 10 seconds. | Y  N  |
| **W4. Walking with Assistance:**  Child is in upright position with the back straight. Child makes sideways or forward steps by holding onto a stable object (e.g. furniture) with one or both hands. One leg moves forward while the other supports part of the body weight. Child takes at least 5 steps in this manner. | Y  N  |
| **W5. Standing Alone:**  Child stands in upright position on both feet (not the toes) with the back straight. The legs support 100% of the child’s weight. There is no contact with a person or object. Child stands alone for at least 10 seconds. | Y  N  |
| **W6. Walking Alone:**  Child takes at least 5 steps independently in upright position with the back straight. One leg moves forward while the other supports most of the body weight. There is no contact with the person or object. | Y  N  |
| **Total WHO Milestones Achieved:** | **/ 6** |

Assessor Initials\_\_\_\_\_\_\_\_\_\_\_\_

**VIGNOS (patient reported or observed)**

|  |  |
| --- | --- |
| **VIGNOS – record best ability** | **Tick one level only** |
| 1. Walk and climbs stair with/without assistance |  |
| 2. Walks and climbs stairs with aid or railing |  |
| 3. Walks and climbs stairs slowly with aid or railing (more than 25 seconds for eight standard steps) |  |
| 4. Walks unassisted and rises from chair; cannot climb stairs |  |
| 5. Walks unassisted; cannot rise from chair; cannot climb stairs |  |
| 6. Walks only with assistance or walks independently with leg braces |  |
| 7. Walks in leg braces, but requires assistance for balance. |  |
| 8. Maintains standing with leg braces, but is unable to even with assistance. |  |
| 9. In wheelchair. |  |
| 10. Confined to bed. |  |

VIGNOS SCORE:\_\_\_\_\_\_\_

**Adapted Brooke (Entry Item from RULM - observed)**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **0** | **1** | **2** | **3** | **4** | **5** | **6** |
| No useful | Can use hands | Can raise 1 or 2 | Can raise | Can raise both | Can raise both | Can abduct both |
| function of | to hold pencil or | hands to mouth | standardized | arms | arms | arms |
| hands. | pick up a token | but cannot raise | plastic cup with | simultaneously | simultaneously | simultaneously |
|  | or drive a | a cup with a | 200g weight in it | to shoulder | above head only | elbows in |
|  | powered chair, | 200g weight in it | to mouth using | height with or | by flexing the | extension in a |
|  | use phone key | to mouth | both hands if | without | elbow | full circle until |
|  | pad |  | necessary. | compensation. | shortening | they touch |
|  |  |  |  | Elbow bent or in | circumference | above the head. |
|  |  |  |  | extension | of the |  |
|  |  |  |  |  | movement |  |
|  |  |  |  |  | /using accessory |  |
|  |  |  |  |  | muscles) |  |

BROOKE SCORE:\_\_\_\_\_\_\_

Assessor Initials\_\_\_\_\_\_\_\_\_\_\_\_

**Additional Information**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Height (metres) |  | Respiratory | Value in litres | Percent predicted |
| Weight (kg) |  | FVC sitting |  |  |
| Head circumference (cm) < 2 years only |  | FVC Lying |  |  |
| Chest circumference (cm) < 2 years only |  | PCF |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **1. Summary of Contractures –**  **Not assessed** | **RIGHT** | Comments field | **LEFT** | Comments field |
| Shoulder contractures? | No / Mild / Mod / Severe |  | No / Mild / Mod / Severe |  |
| Elbow contractures? | No / Mild / Mod / Severe |  | No / Mild / Mod / Severe |  |
| Wrist contractures? | No / Mild / Mod / Severe |  | No / Mild / Mod / Severe |  |
| Finger contractures? | No / Mild / Mod / Severe |  | No / Mild / Mod / Severe |  |
| Hip contractures? | No / Mild / Mod / Severe |  | No / Mild / Mod / Severe |  |
| Knee contractures? | No / Mild / Mod / Severe |  | No / Mild / Mod / Severe |  |
| Ankle contractures? | No / Mild / Mod / Severe |  | No / Mild / Mod / Severe |  |
| Mild = no influence on function  Moderate = impacts function  Severe = makes tasks impossible or extremely difficult | | | | |

**2. Does the patient currently use an assistive device for mobilising, standing or walking?**

🞏 No assistive device used

🞏 Yes – specify below

|  |  |  |  |
| --- | --- | --- | --- |
| For other: *please specify*: eg standing frame, mobile arm support, Swivel walker | Part time | Full time | Details / Specify / |
| Walker/ walking frame |  |  |  |
| Cane/stick / walking poles |  |  |  |
| Standing frame |  |  | Sessions per week |
| Other |  |  |  |
| Other |  |  |  |

**3. Does the patient currently use any orthotics?**

🞏 No orthotics used

🞏 Yes – specify below

|  |  |  |
| --- | --- | --- |
| For other: *please specify*: eg standing frame, mobile arm support, Swivel walker / KAFO’s | Yes / No / Unknown | Circle why and when used |
| AFO’s | Yes No Unknown | Resting / Functional / Day / Night |
| Knee immobilsers / splints | Yes No Unknown | Resting / Functional / Day / Night |
| Supramalleolar orthosis (SMO’s) | Yes No Unknown | Resting / Functional / Day / Night |
| Shoe inserts / insoles | Yes No Unknown | Resting / Functional / Day / Night |
| Knee ankle-foot orthoses (KAFO’s) | Yes No Unknown | Resting / Functional / Day / Night |
| Handsplints | Yes No Unknown | Resting / Functional / Day / Night |
| Spinal jacket / TLSO - | Yes No Unknown | Resting / Functional / Day / Night |
| Other | Yes No Unknown | Resting / Functional / Day / Night |

Assessor Initials\_\_\_\_\_\_\_\_\_\_\_\_

**4. Does the patient use a wheelchair?**

🞏 No, wheelchair not used

|  |  |  |
| --- | --- | --- |
|  | Part time  From what age? | Full time  From what age? |
| Electric wheelchair | From age of | From age of |
| Motorised scooter | From age of | From age of |
| Manual wheelchair | From age of | From age of |
| Other:Eg power assisted manual……………………………….. | From age of | From age of |

**5. Does the patient currently undertake any Physiotherapy?**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Physiotherapy** | Yes No  circle | Number of times a week | Total hours performed by **parents** per week | Hours performed by **physiotherapist** per week | Hours performed by **carer / support worker** / **other** per week |
| **Stretches (Example given)** | Y N | X  **7** | **3.5** *(as do ½ hr stretches every day)* | **0.25** *(as seen for 1 hr stretch once a month)* | **1.0** *(as seen twice a week for ½ hr at school)* |
| Stretches / ROM | Y N | X |  |  |  |
| Promoting function | Y N | X |  |  |  |
| Strengthening exercise | Y N | X |  |  |  |
| Aerobic exercise (includes PE) | Y N | X |  |  |  |
| Water based Activity, Hydrotherapy | Y N | X |  |  |  |
| Horseriding / Hippotherapy | Y N | X |  |  |  |
| Other (martial arts, dance) | Y N | X |  |  |  |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **6. Does the patient receive regular (year round) therapy** | No | Yes | Start date | Ongoing | Stop date and reason | Not known |
| Physiotherapy – all types from above |  |  |  |  |  |  |
| Occupational Therapy for assessment of home enviroment |  |  |  |  |  |  |
| OT for promoting function |  |  |  |  |  |  |
| SLT |  |  |  |  |  |  |

Reason stopped therapy: 1 No perceived benefit of family / patient. 2 – No perceived benefit by provider. 3 – Lack of insurance cover.

4 - Not available through health care provider

**7. Does the patient fall?**

🞏 No

🞏 Yes **If Yes please select on on option and add number of times** (e.g. x2 – Weekly)

|  |  |
| --- | --- |
|  | Number of times |
| Daily |  |
| Weekly |  |
| Monthly |  |
| Yearly |  |

# Centre ID\_\_\_\_Smartnet No:\_SN\_\_\_\_\_\_\_\_\_Pt ID\_\_\_\_\_Date \_ \_ / \_ \_ \_ / \_ \_ \_ \_ Assessor\_\_\_\_\_\_\_\_\_\_\_\_Signature\_\_\_\_\_\_\_\_\_\_\_\_

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**8.** **Does the patient get any pain?**

🞏 No

🞏 Yes – if yes refer to below

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **P1** | **P2** | **P3** | **P4** |
| Location of pain |  |  |  |  |
| **When** **do you get pain?** – can tick more than 1 box. If always, can tick all | | | | |
| At rest |  |  |  |  |
| During activity |  |  |  |  |
| After activity |  |  |  |  |
| **Frequency of Pain** – tick one box | | | | |
| Present every day |  |  |  |  |
| Pain at least once a week |  |  |  |  |
| Pain at least once a month |  |  |  |  |
| Less than once a month |  |  |  |  |
| **Impact of pain on function –** tick one box | | | | |
| Mild |  |  |  |  |
| Moderate |  |  |  |  |
| Severe |  |  |  |  |
| Pain rating |  |  |  |  |

Mild = no influence on function

Moderate = impacts function

Severe = makes tasks impossible or extremely difficult

|  |  |
| --- | --- |
| **Impact of fatigue on function - key** | **Tick** |
| Mild = no impact on everyday functioning |  |
| Moderate = some impact on everyday functioning |  |
| Severe - significant limitation on everyday functioning |  |

**8. Does the patient experience fatigue?**

🞏 No

🞏 Yes **If Yes please select level of fatigue.**

**Thank you**