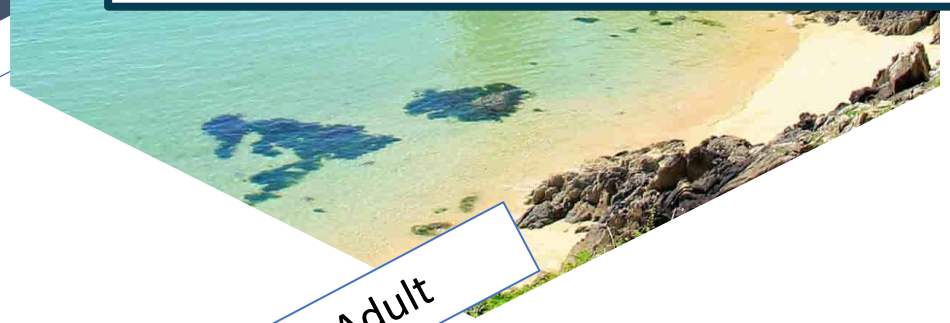
Handicap acquis dans l'enfance : perspectives à l'échelle de la vie
Exemple de la paralysie cérébrale



Dr Gwenael Cornec

#BecomeAdult

BEaCHiLD - Innovons ensemble -

CHU BREST CENTRE HOSPITALIER UNIVERSITAIRE

Introduction et objectifs

Pourquoi aborder la PC à l'échelle de la vie ?

Du modèle pédiatrique traditionnel vers une approche par parcours de vie

- Historiquement diagnostic et circuit coordonnés en pédiatrie… mais les pédiatres ne « grandissent » pas
- Lésion « stable » …?
  => complications neurodéveloppementales
  => complications secondaires et dégradation fonctionnelle

Impact pratique en MPR

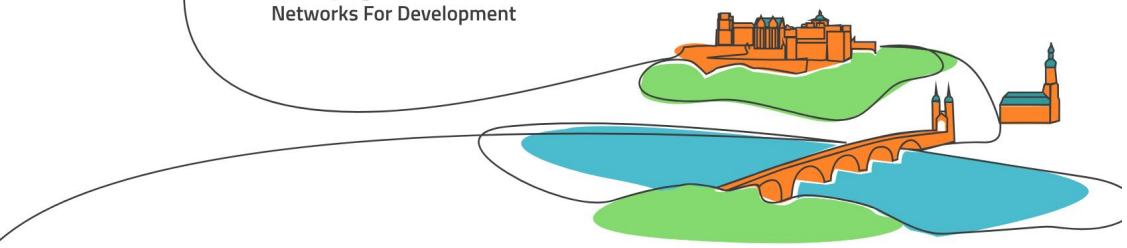
- Suivi ? Accès aux soins ?
- Autonomisation ?
- Participation ?
- Prévention ?
- Vieillissement ?

Towards a lifecourse perspective

Life Course Working Group

June 24–28, 2025
EACD & IAACD
Heidelberg Germany

Developing Networks –
Networks For Development



European Academy of
Childhood Disability

European Academy of
Childhood-onset Disability

It's for life: reframing CP and other childhood onset disabilities as life-long conditions

Physical health challenges for adults

June 24–28, 2025
EACD & IAACD
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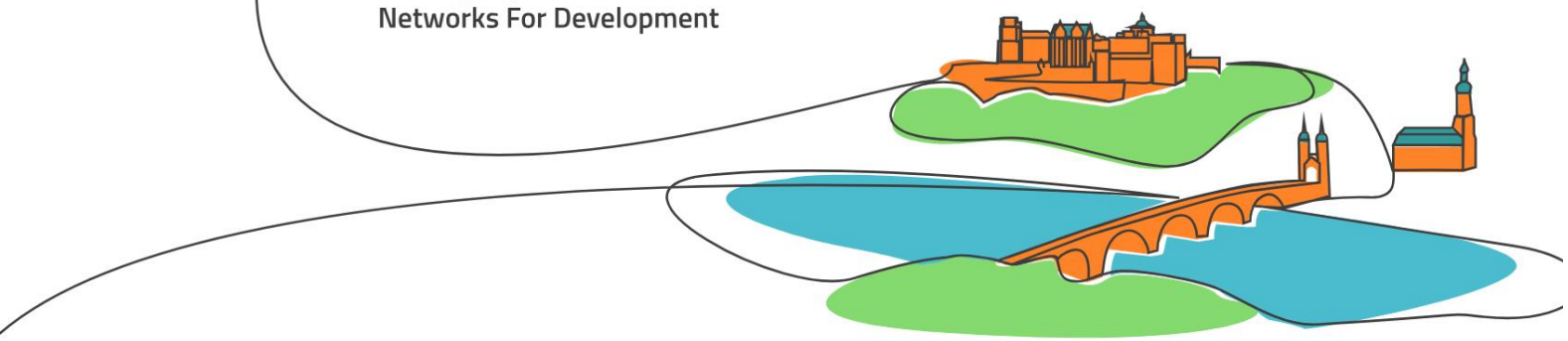
Developing Networks –
Networks For Development



Miriam Creeger, London, UK
Gwenael Cornec, Brest, France

UP The Adult Cerebral Palsy Movement

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LATIM

PERSPECTIVE

Reframing Cerebral Palsy as a Lifelong Physical Disability

Author: Mark D. Peterson, Ph.D. Author Info & Affiliations

The NEW ENGLAND JOURNAL of MEDICINE

Published November 2, 2024 | N Engl J Med 2024;391:1668-1670 | DOI: 10.1056/NEJMp2403366

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"Yet there are currently more adults than children living with CP in the United States."
"I believe CP should be recognized for what it is: the most common lifelong physical disability in the world."

EXPERT-CONSENSUS REPORT

Proposed updated description of cerebral palsy

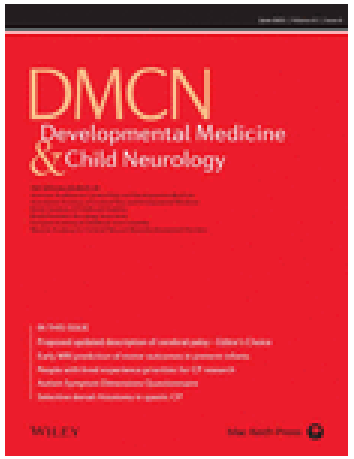
Bernard Dan[1,2,3] | Peter Rosenbaum[1,4] | Lucinda Carr[1,5] | Martin Gough[1,6]
John Coughlan[7,*] | Nonyelum Nweke[7,8,*]

THE LANCET

SEMINAR · Online first, June 20, 2025

Cerebral palsy

Prof Iona Novak, PhD [a,b] · Michelle Jackman, PhD [b,c] · Megan Finch-Edmondson, PhD [b] · Prof Michael Fahey, PhD [d,e]



Cerebral palsy (CP) is an early-onset lifelong neurodevelopmental condition characterized by limitations in activity due to impaired development of movement and posture, manifesting as spasticity, dystonia, choreoathetosis, and/or ataxia. It results from maldevelopment attributed to dysplasia of or injury to the fetal or infant brain that is not degenerative, although the manifestations may change with age. The phenotype of CP is complex and heterogeneous, with each person experiencing a unique presentation. In addition to motor dysfunction, people with CP frequently encounter primary and secondary impairments across various areas of development and functioning, which can significantly impact their participation in daily life.


collège français des
enseignants universitaires de
Cofemer
médecine physique
et de réadaptation

Clinique

Plaintes des patients Hirsh 2011

- Douleur
- Fatigue – physique (fatigabilité) et psychologique

- Trouble de l'équilibre

- Faiblesse et déclin fonctionnel

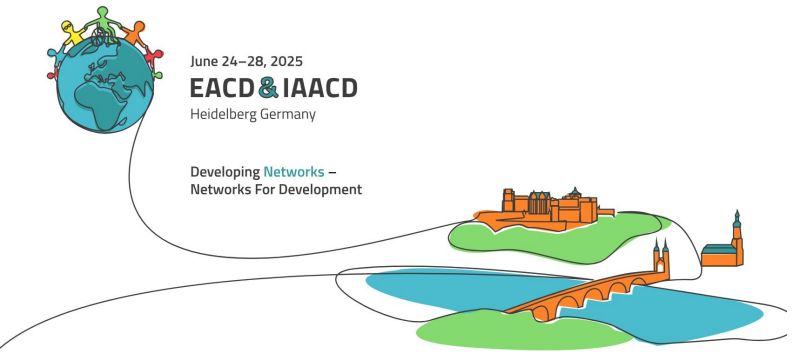
➢ Restriction de participation

Jahnsen 2003, Opheim 2009, van der Slot 2012, Morgan 2014, van der Slot 2020, Puce 2021, Rodby-Bousquet 2021, Gannotti 2024, van Rijssen 2025,.

Risques à l'échelle de la vie

Prévalence plus élevée de :

- Douleur *(65% van Gorp 2020, 24-89% - Ryan 2025, RRx2-3 pour tous les types – Peterson 2021)*, fatigue
- Arthrose, ostéoporose, fracture ostéoporotique (!myélopathie cervicarthrosique!)
- Chutes (GMFCS (I)II-III(IV), ataxique!) *(86%/12mois - Esterley 2025, Shah 2023…)*
- Pathologies cardio-vasculaires : HTA, IDM, AVC *(RRx1,64, x2,32 & x5,53 – Ryan 2022)*
- Pathologies psychiatriques *(20% tb humeur, 20% tb anxieux (RRx2), 2,8% schizophrénie, 1,2% tb personnalité (RRx4), 4,7% tb addictif (RRx1,5) – Whitney 2019)*
- Asthme *(28% - van Gorp 2020)* et autres pathologies respiratoires
- Epilepsie *(29% - van Gorp 2020)*
- Démence (x7 <65ans, x2 >65ans – Mahmoudi 2022)…
- Pathologies rénales (peu de données neuro-uro…) et hépatiques
- Dénutrition/obésité, trouble de déglutition, constipation…
- Trouble du sommeil (!SAS!)



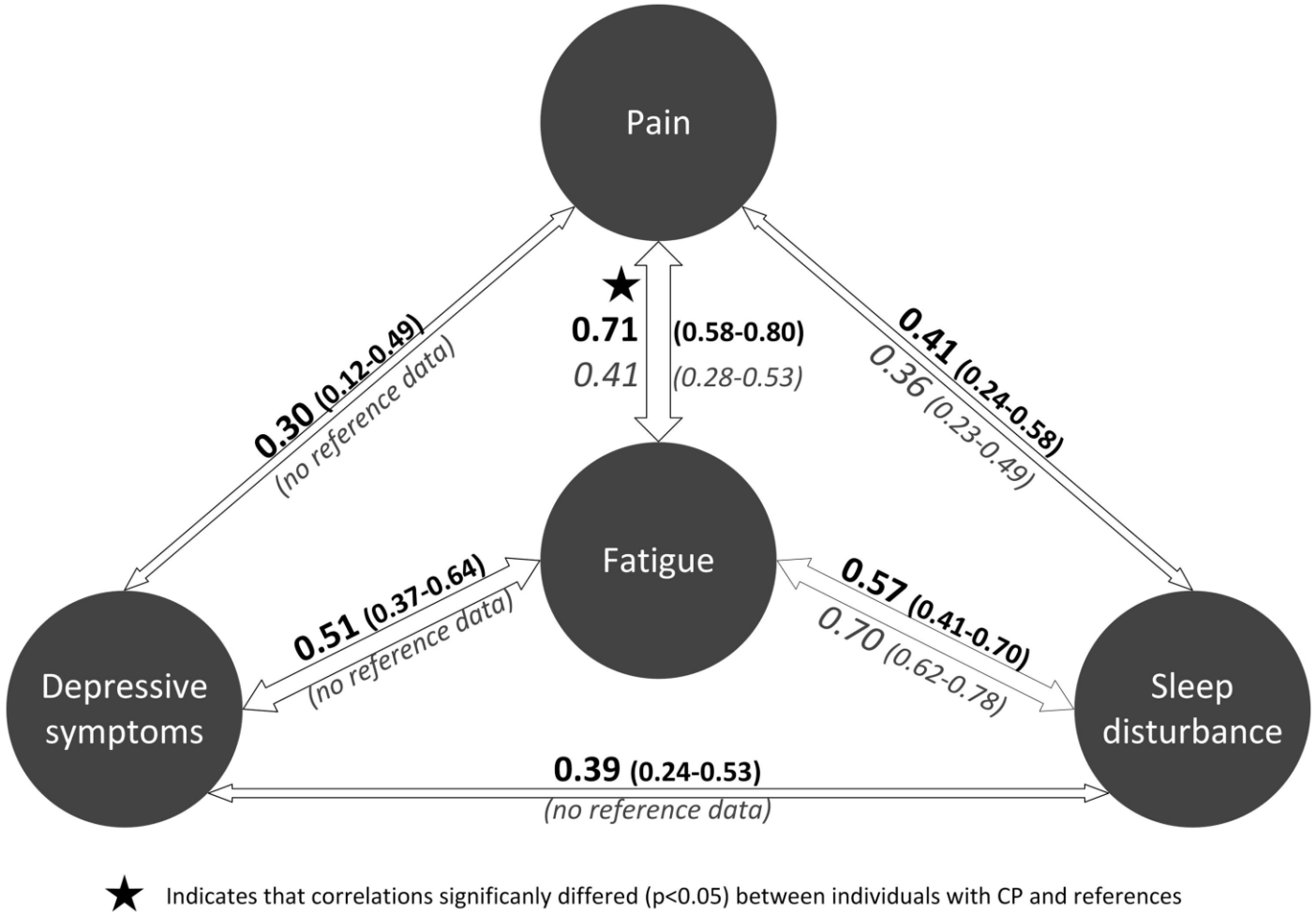
van der Slot et al, Pain in adults with cerebral palsy: A systematic review and meta-analysis of individual participant data. Ann Phys Rehabil Med. 2020

Trinh et al, Prevalence of and risk factors for osteoporosis and fragility fracture in adults with cerebral palsy: A systematic review. Dev Med Child Neurol. 2025

van Gorp et al, Epidemiology of Cerebral Palsy in Adulthood: A Systematic Review and Meta-analysis of the Most Frequently Studied Outcomes. Arch Phys Med Rehabil. 2020

Ryan et al, Prevalence and incidence of chronic conditions among adults with cerebral palsy: A systematic review and meta-analysis. Dev Med Child Neurol. 2023

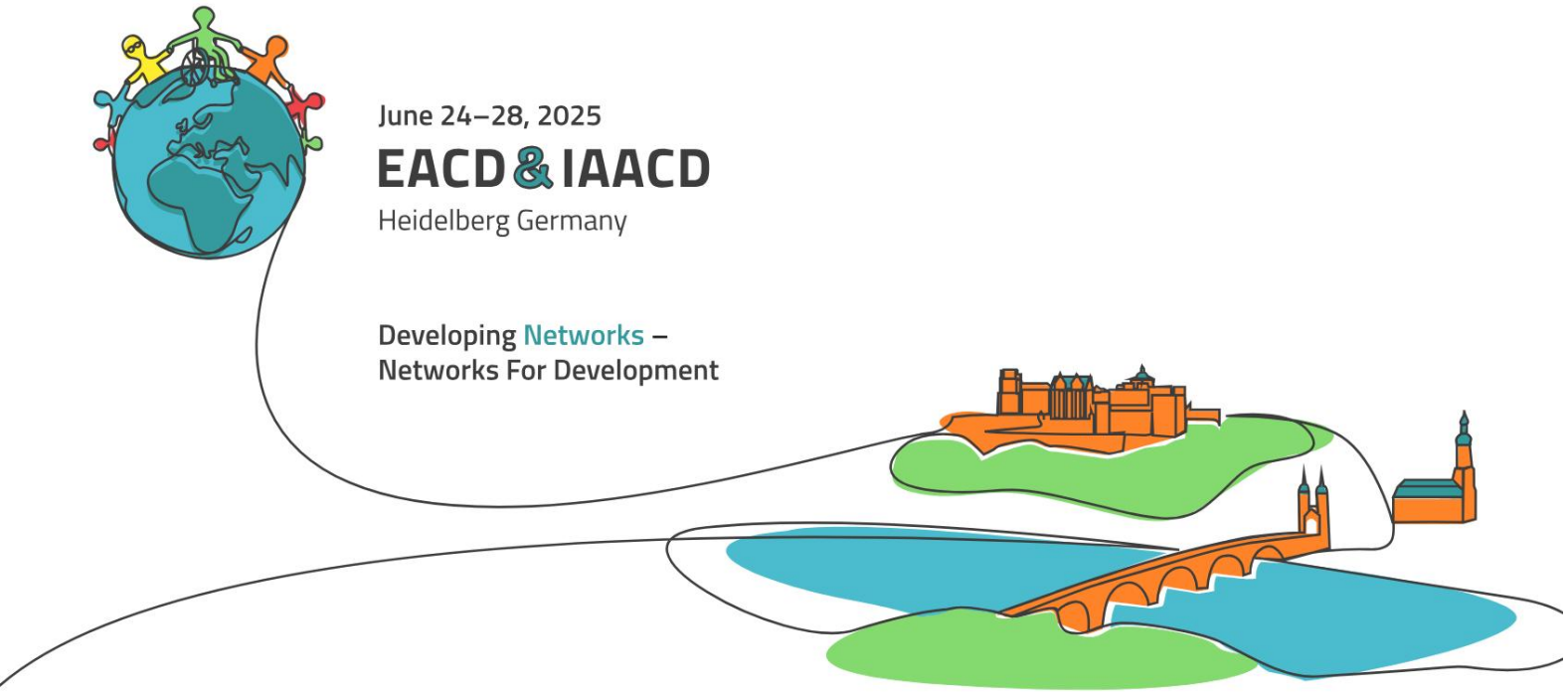
Whitney et al. Prevalence of Mental Health Disorders Among Adults With Cerebral Palsy: A Cross-sectional Analysis. Ann Intern Med. 2019

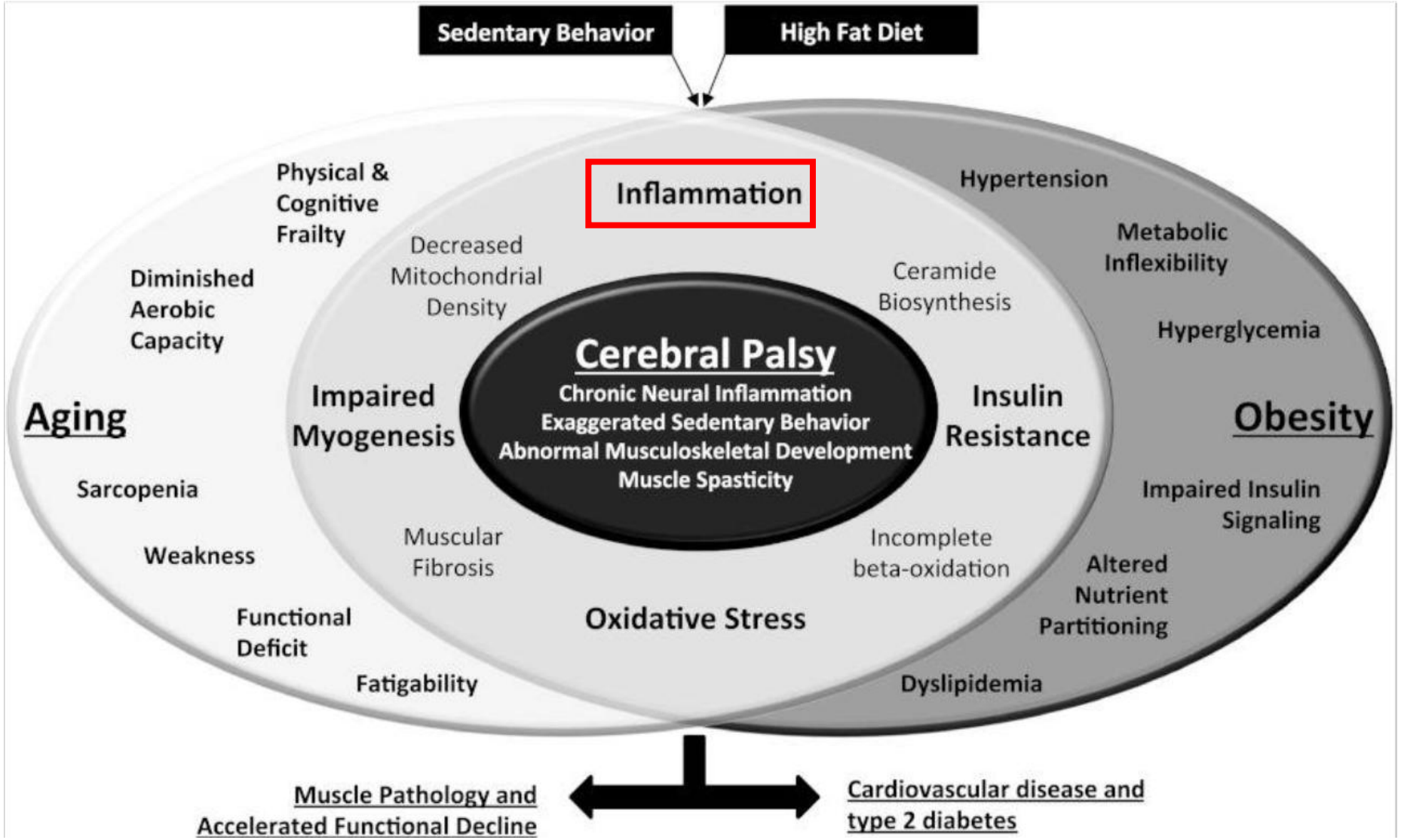


van Gorp M, Dallmeijer AJ, van Wely L, et al.
Pain, fatigue, depressive symptoms and sleep disturbance in young adults with cerebral palsy.
Disabil Rehabil. 2021

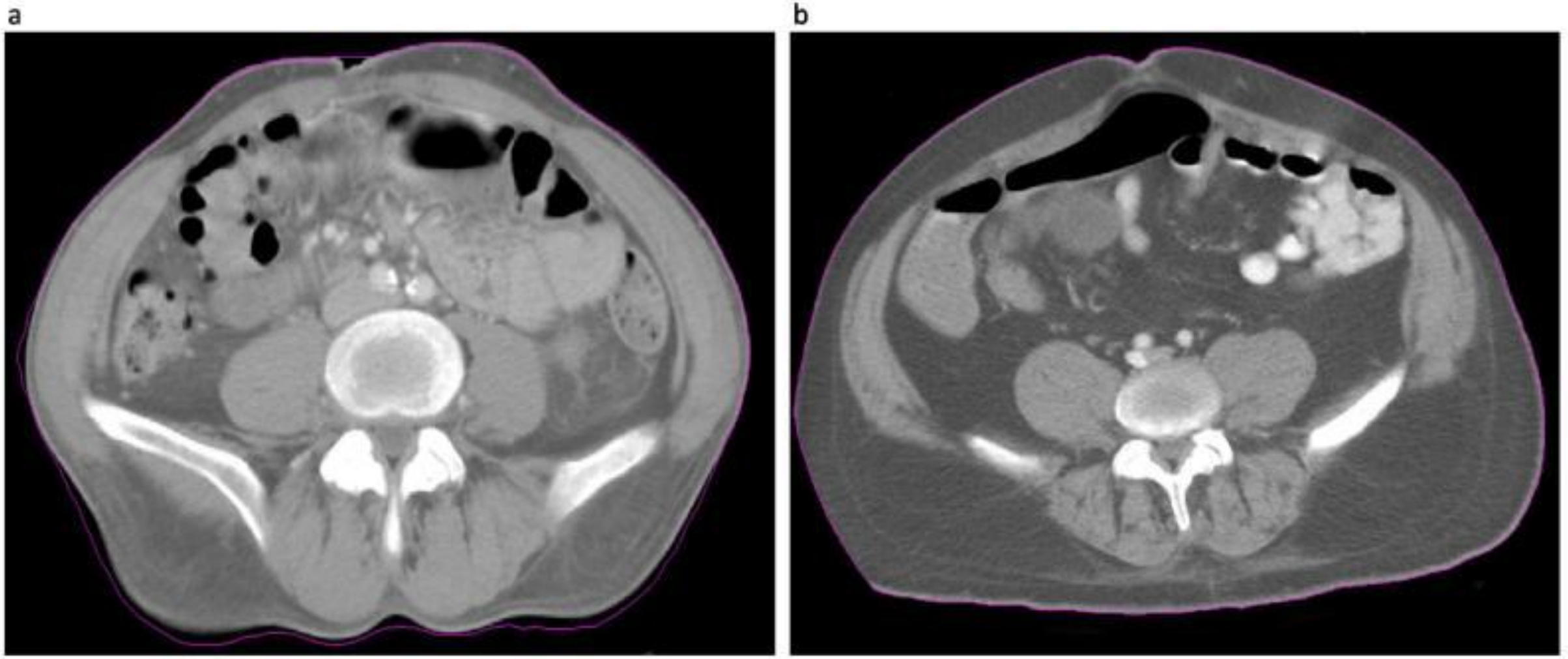
Keynote
The most common physical disability in the word

Mark Peterson – US - Michigan



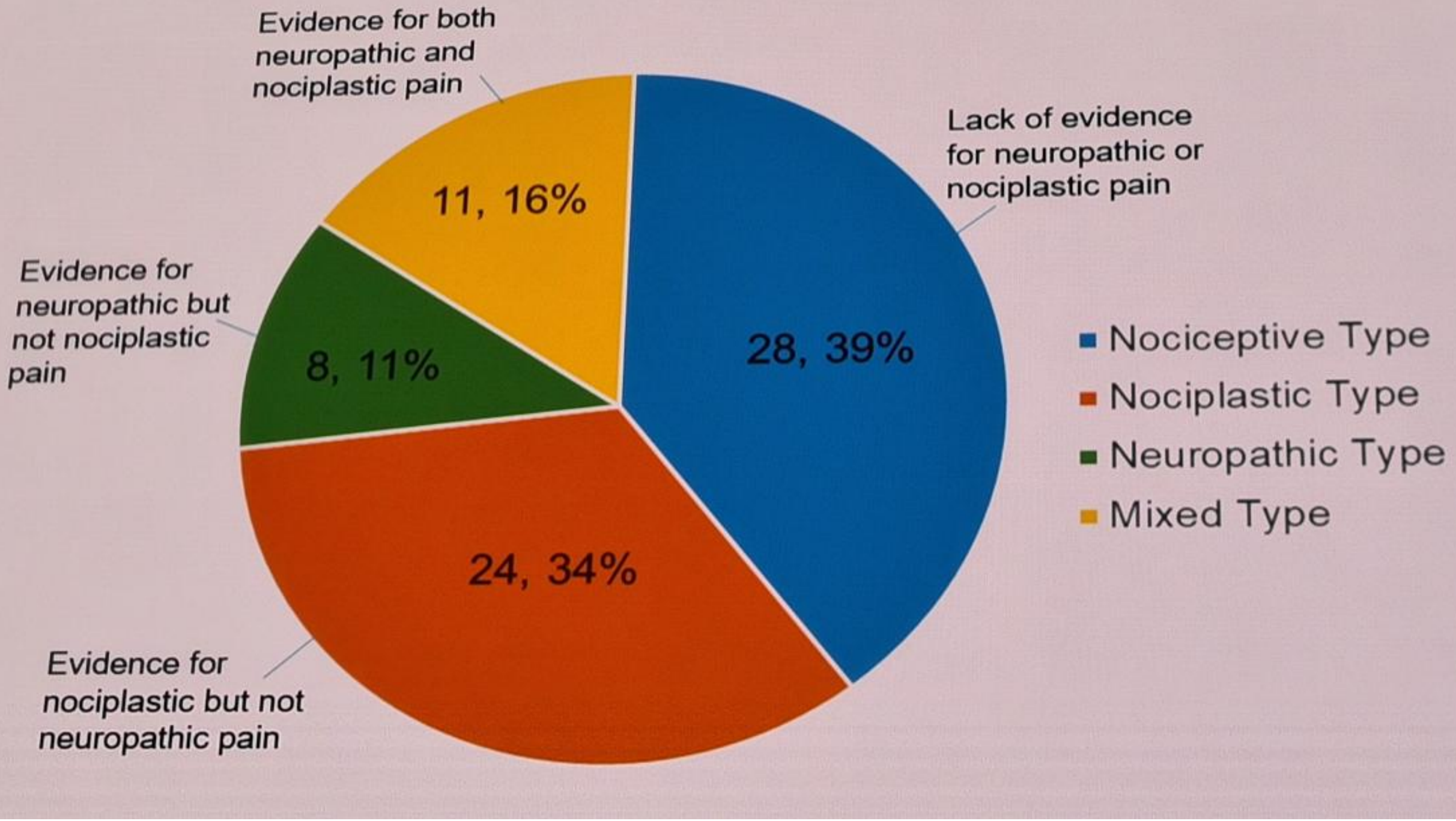


Peterson MD, Gordon PM, Hurvitz EA, Burant CF. Secondary muscle pathology and metabolic dysregulation in adults with cerebral palsy. Am J Physiol Endocrinol Metab. 2012



Computed tomography image at vertebral level L4, depicting trunk adiposity distribution and muscle size in: (a) a 53-year-old, neuro-typical male (65 kg body mass), and (b) a 54-year-old male with CP (66 kg body mass).

Peterson MD et al. Greater Adipose Tissue Distribution and Diminished Spinal Musculoskeletal Density in Adults With Cerebral Palsy. Arch Phys Med Rehabil. 2015


Evidence for both neuropathic and nociplastic pain
11, 16%
Lack of evidence for neuropathic or nociplastic pain
28, 39%
Evidence for neuropathic but not nociplastic pain
8, 11%
24, 34%
Evidence for nociplastic but not neuropathic pain
Nociceptive Type
Nociplastic Type
Neuropathic Type
Mixed Type

Medication and Therapy Profiles for Pain and Symptom Management Among Adults With Cerebral Palsy.

Peterson M et al. Mayo Clin Proc Innov Qual Outcomes. 2025

	No Pain (n=5529, 13.3%)	Neuropathic Pain/ Nociceptive Pain (n=1856, 4.5%)	Neuropathic Pain/ Nociceptive Pain/ Nociplastic Pain (n=5229, 12.6%)	Nociceptive Pain (n=15,973, 38.4%)	Nociceptive Pain/ Nociplastic Pain (n=11,887, 28.6%)
Nonperioperative opioids, n (%)	872 (15.8%)	1046 (56.4%)	4175 (79.8%)	5149 (32.2%)	6054 (50.9%)

Opioids are associated with small improvements versus placebo in pain and function, and increased risk of harms at short-term (1 to <6 months) follow-up; evidence on long-term effectiveness is very limited, and there is evidence of increased risk of serious harms that appear to be dose dependent.

Chou 2020 / 2022

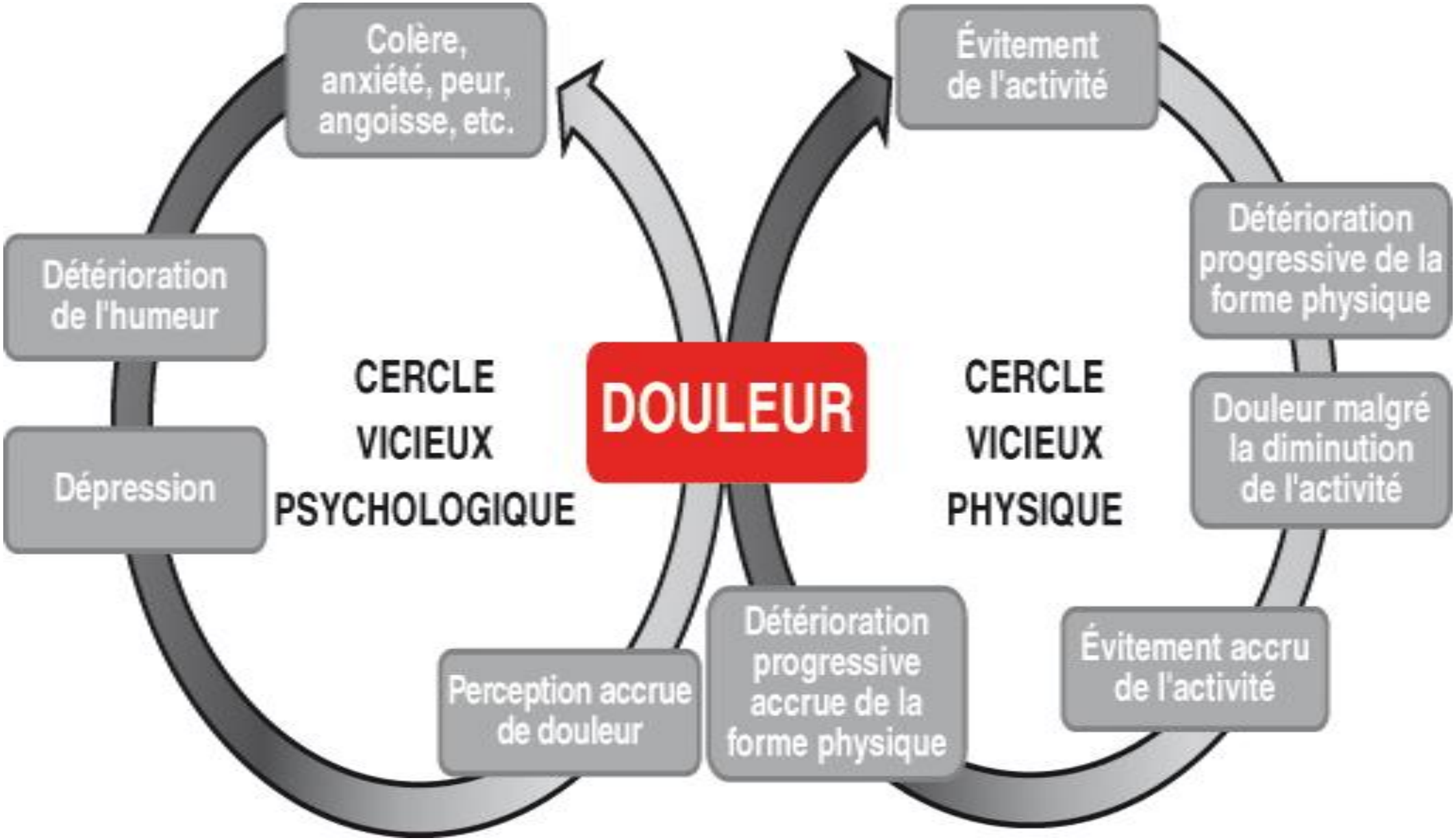
From childhood to adulthood: health care use in individuals with cerebral palsy.

Roquet M, Garlantezec R, Remy-Neris O, et al. *Dev Med Child Neurol*. 2018

GMFCS I-III

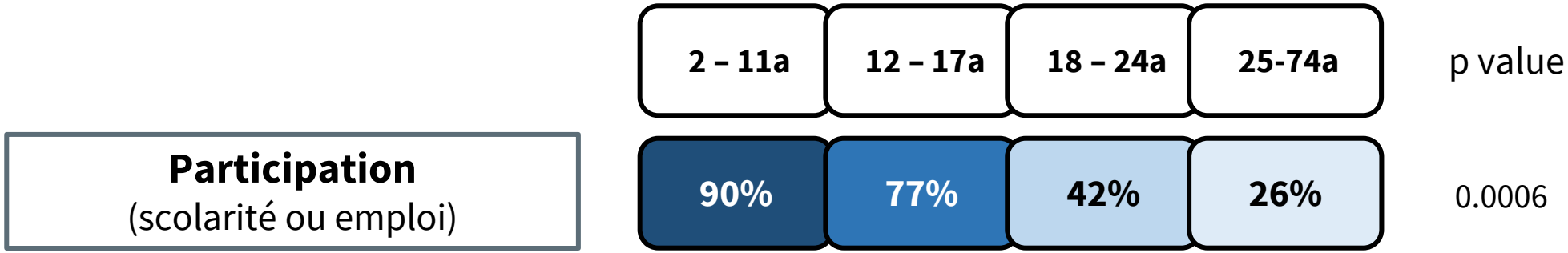
Age	2–5	6–11	12–17	18–24	25–39	≥40	*p*
Traitement							
Au moins 1	32	29	38	45	60	77	<0.001
Antalgique	2	1	3	7	13	30	<0.001
Psychotropes	2	5	3	17	18	28	0.001
Suivi MPR	90	78	87	52	40	46	<0.001
Kiné	98	84	95	90	80	70	<0.001
Ergo	49	51	22	21	15	2	<0.001

Questionnaire, 282 adultes et 230 enfants en Bretagne


Colère, anxiété, peur, angoisse, etc.
Évitement de l'activité
Détérioration de l'humeur
Détérioration progressive de la forme physique
CERCLE VICIEUX PSYCHOLOGIQUE
DOULEUR
CERCLE VICIEUX PHYSIQUE
Dépression
Douleur malgré la diminution de l'activité
Perception accrue de douleur
Détérioration progressive accrue de la forme physique
Évitement accru de l'activité

Et la participation ?

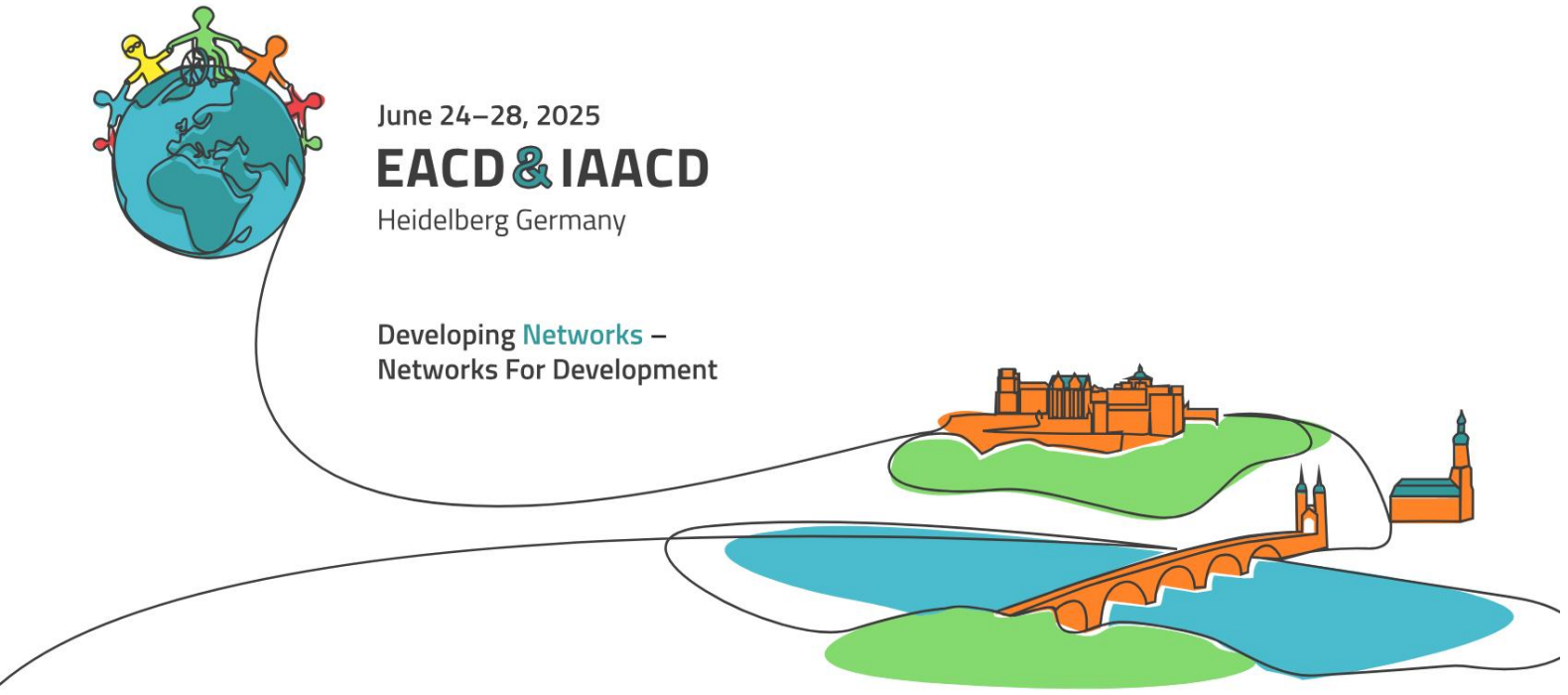
- Liée à la sévérité du tableau clinique (déficience intellectuelle, trouble de la communication, forme bilat., habileté manuelle)
- ≈40% des adultes en emploi, 30% logement autonome *(Van gorp 2020)*
- Registre suédois >1900 adultes :
  - 19% en emploi dont la moitié à plein-temps, 45% avec activités en centre spécialisé *(Hedberg-Graff et al. Disabil Health J. 2026)*
  - 1/8 vit en couple
  - logement autonome : 7% avant 20 ans, 55% 25-29ans, 72% 40-45ans
    - avec pour facteur explicative écrasant la quantité d'aide humaine (similaire en Suède quel que soit le GMFCS de ce fait) *(Pettersson et al. Front Neurol 2021)*



Contexte de soins

Taking a lifecourse health development approach – looking at the determinants of health

Access to health services - Europe



Jennifer Ryan, Dublin, Ireland
Gwenael Cornec, Brest, France

ESPaCe

FONDATION PARALYSIE CÉRÉBRALE

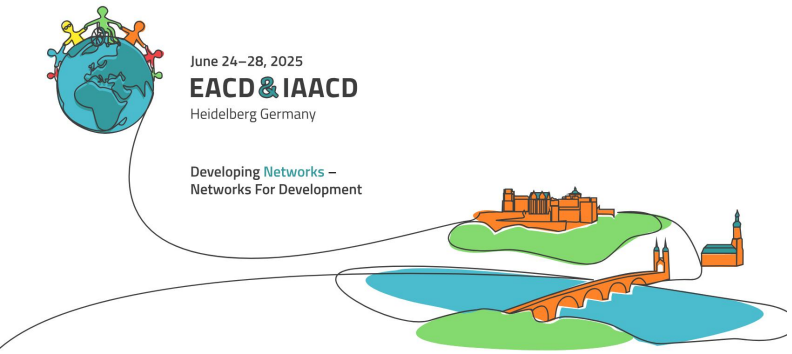
Enquête Satisfaction Paralysie Cérébrale : Besoins, barrières et attentes vis-à-vis de la rééducation pour les enfants et adultes vivant avec une paralysie cérébrale

Cornec et al, APRM 2019, Cornec et al, Front Neurol 2022

Participants
n = 997

2-11 yo : 34%
12-17 yo : 14%
18-24 yo : 12%
≥ 25 yo : 40%

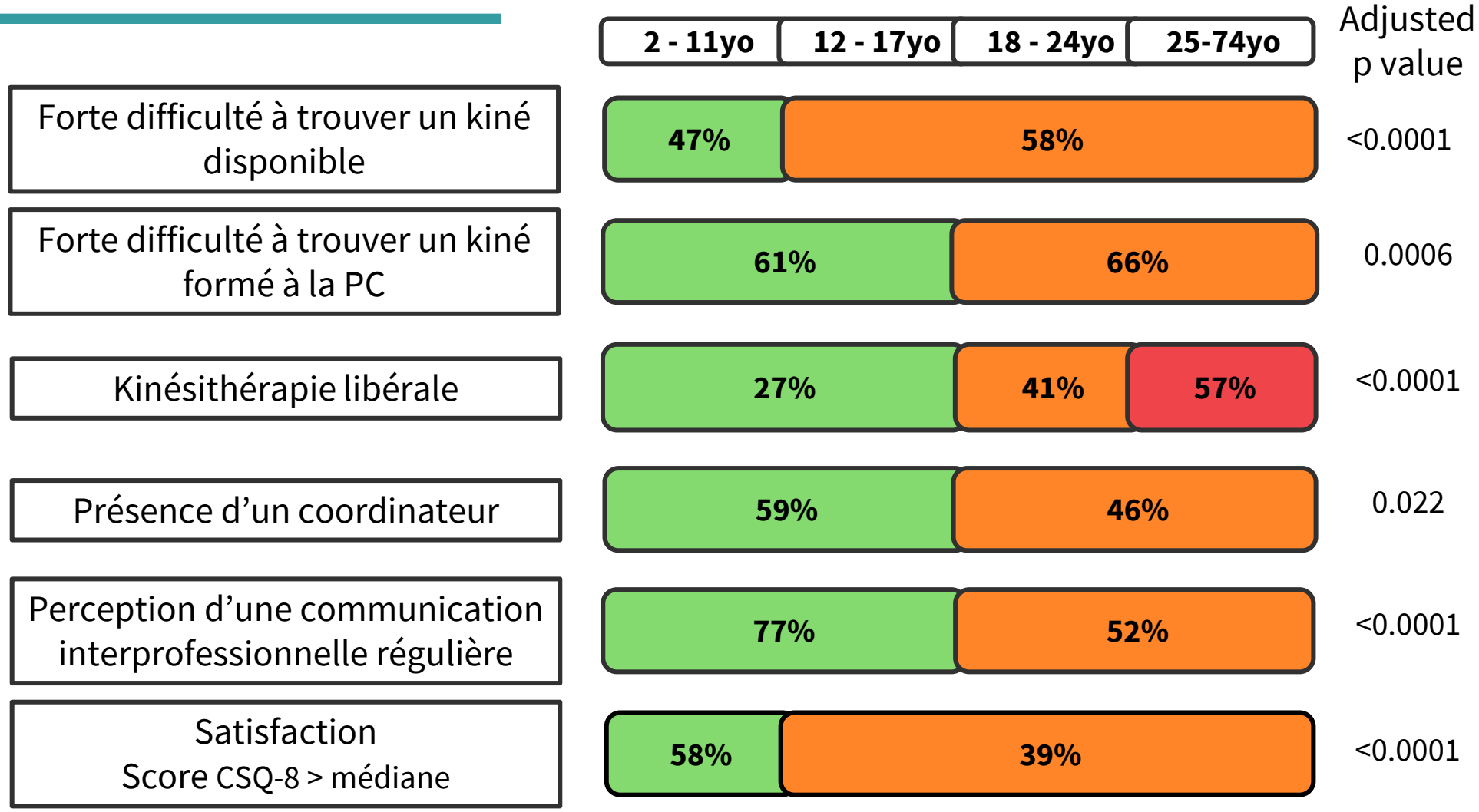
	2 - 11yo	12 - 17yo	18 - 24yo	25-74yo	Adjusted p value
Rééducation en cours	99%		92%		<0.0001
Multidisciplinarité	82%	64%	41%		<0.0001
Kiné hebdomadaire ≥ 90min	51%		42%	32%	<0.0001



Moins de besoin ?

Difficulté d'accès ?

The ESPaCe national survey



June 24–28, 2025
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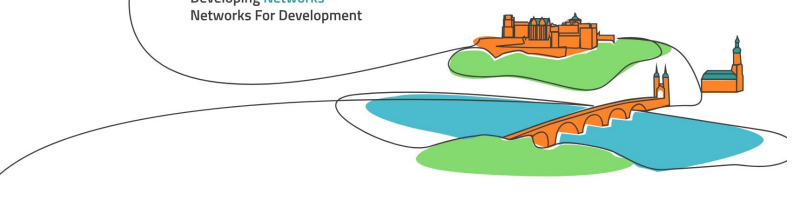
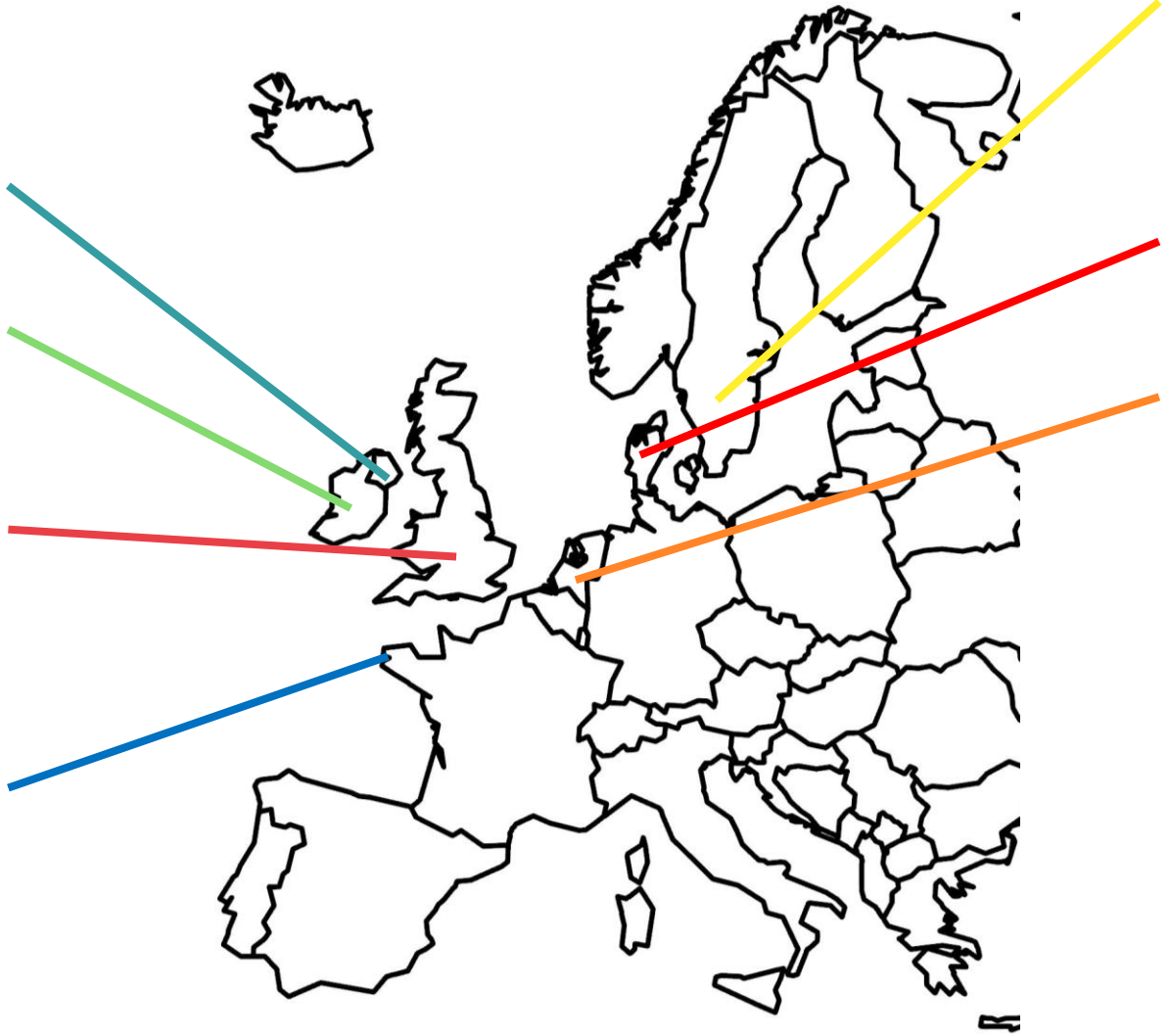


The use and outcomes of motor rehabilitation services among people with cerebral palsy change across the lifespan. Cornec et al. Front Neurol. 2022

Access to rehabilitation services in Europe

Adults with cerebral palsy – a quick review of recent literature



MacDowell, 2015

Ryan, 2021, 2022…
Manikandan, 2022…

Shah 2022
Manikandan, 2023
Cook, 2023

Pons, 2017
Roquet, 2018
Cornec, 2021, 2022

Andersson, 2007
Petterson, Rodby-Busquet 2021

Normann, 2020

Nieuwenhuijsen, 2008

European studies :

- Rioual 2024 : SPARCLE3 (France, Germany, Italy, Portugal, Sweden)
- Papavasiliou 2024 (58 experts from 26 countries)

Que proposer ?

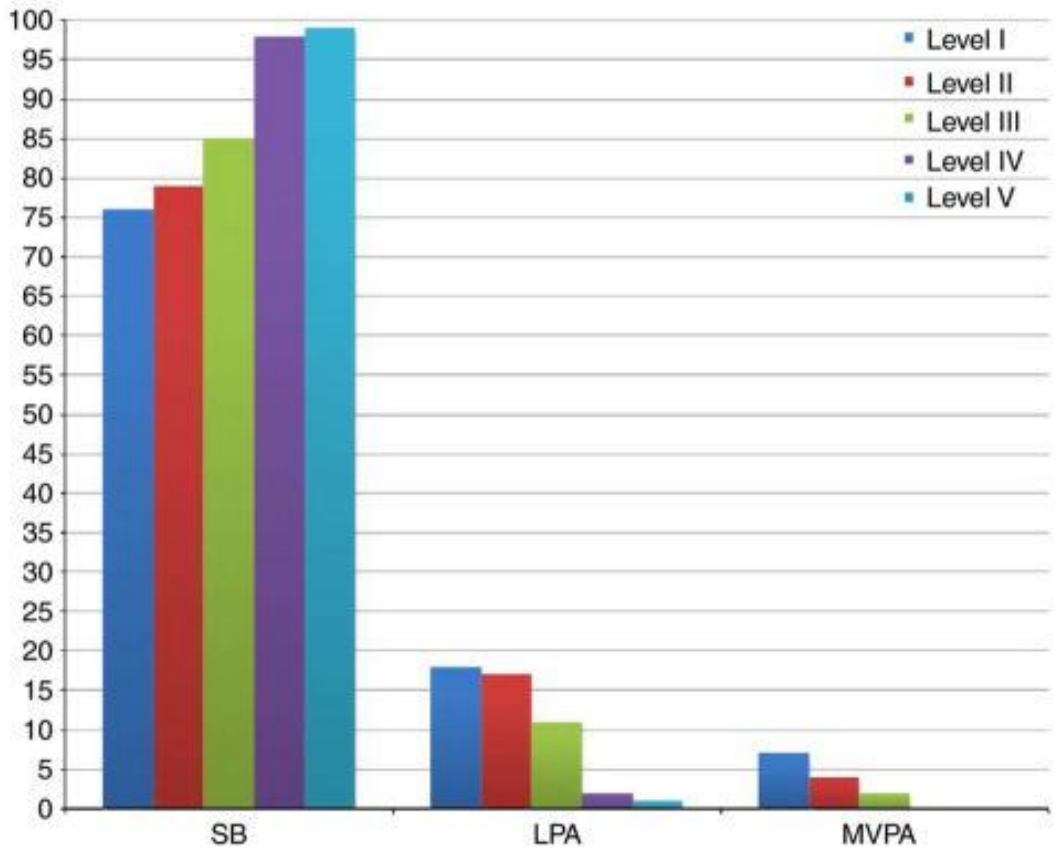
▸ Dev Med Child Neurol. Author manuscript; available in PMC: 2016 Aug 1.

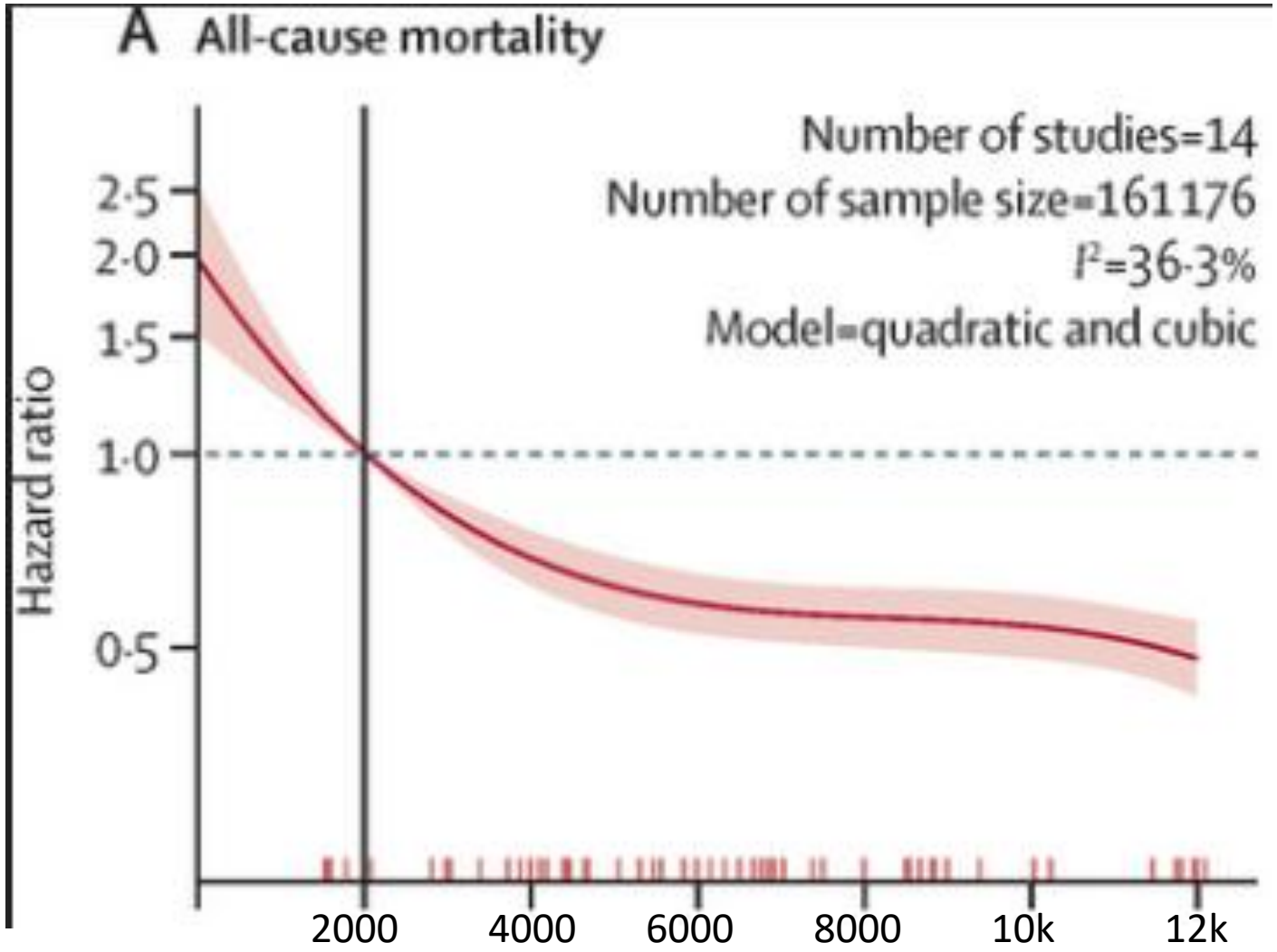
Published in final edited form as: Dev Med Child Neurol. 2016 Feb 7;58(8):798–808. doi: 10.1111/dmcn.13053

Exercise and Physical Activity Recommendations for People with Cerebral Palsy

Olaf Verschuren [1,✉], Mark D Peterson [2], Astrid CJ Balemans [3], Edward A Hurvitz [4]

Figure 1. Percentage of time spent in sedentary, light, and moderate to vigorous physical activities across all GMFCS levels.





Ding D, Nguyen B, Nau T, et al. Daily steps and health outcomes in adults: a systematic review and dose-response meta-analysis. *Lancet Public Health*. 2025

Que peut-on améliorer ?

- Approche globale incluant les facteurs physiques, mentaux et sociaux pour améliorer la participation
  - **Transition** & **éducation** & **prévention** & **dépistage** & **coordination**
  - Importance des **“allied health professionals”** et des **objectifs partagés** !
  - **Facteurs de risque modifiables** : sédentarité & inactivité physique, sommeil, régime
  - **Accès** à des soins spécialisés (MPR, traitements neuro-orthopédiques, épilepsie, uro/gyneco/sexo, nutrition…), centres de reference
  - Sortir des centres de rééducation ?
- **Formation** des professionnels de santé à la PC (au handicap acquis dans l’enfance !)
- Evolution des politiques de santé… et d’inclusion professionnelle !!
- Connaître et utiliser les ressources déjà existantes

Devenir acteur d'une santé accessible et inclusive

HANDI CONNECT.fr

Vieillissement
Paralysie cérébrale
Tous professionnels de santé

N°H64

Paralysie cérébrale et vieillissement : les points de vigilance clinique

Version : Mars 2025

Attention à l'arbre qui cache la forêt

Suivi régulier en médecine physique et de réadaptation (MPR) indispensable, mais ne pas oublier le dépistage des pathologies classiques d'une personne vieillissante.

Ex : myélopathie cervicale, Parkinson, maladies neuromusculaires, douleurs lombaires, cancers...

https://handiconnect.fr/fiches-conseils/paralysie-cerebrale-et-vieillissement-les-points-de-vigilance-clinique


collège français des
enseignants universitaires de
Cofemer
médecine physique
et de réadaptation

Echanges