

CP-Life Research Centre

Cerebral Palsy Lifespan Health
& Well-being Research Centre



RCSI

UNIVERSITY
OF MEDICINE
AND HEALTH
SCIENCES

Development of physical and mental health conditions and health service needs in people with CP; a lifespan perspective

Jennifer Ryan, PhD

Director, CP-Life Research Centre

Senior Lecturer, RCSI

Cerebral palsy: a **child-onset** condition

- The global prevalence of CP in high income countries is **1.6/1,000 live births**
- More than 80% of people with CP will live to at least 58 years
- Estimated that most people with CP have life expectancy similar to the general population
- Approximately 75% of people living with CP are adults

Cerebral palsy: a **child-onset** condition

Childhood condition  Child-onset condition

Lifespan perspective on...

- Policy
- Service development and delivery
- Funding allocation
- Research
- Parents' perceptions of CP
- Young people's experience



Volume 51, Issue s4

Special Issue: Adults with Cerebral Palsy: A workshop to define the challenges of treating and preventing the secondary musculoskeletal and neuromuscular complications in this rapidly growing population.

Pages: 1-184

October 2009



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DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

REVIEW

Health, mortality, and wellness issues in adults with cerebral palsy

MARGARET A TURK MD

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

REVIEW

The potential metabolic consequences of cerebral palsy: inferences from the general population and persons with spinal cord injury

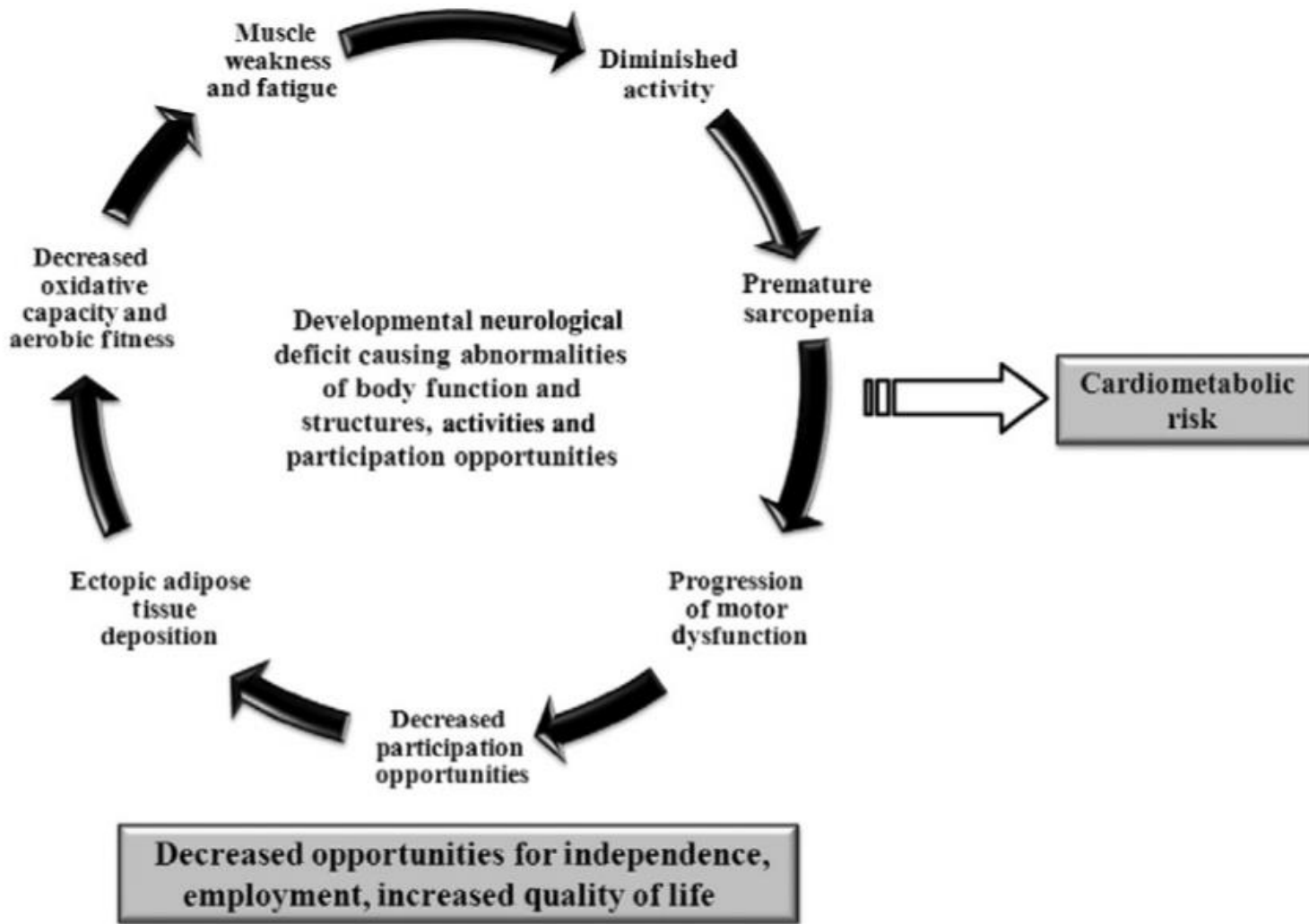
WILLIAM A BAUMAN MD

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

REVIEW

Muscle deficits in cerebral palsy and early loss of mobility: can we learn something from our elders?

ADAM SHORTLAND PHD



Causes of excess mortality in cerebral palsy

David Strauss* PhD FASA, Department of Statistics,
University of California, Riverside;

William Cable MD, Fairview Developmental Center, Costa
Mesa;

Robert Shavelle PhD, Department of Statistics, University of
California, Riverside, CA 92521-0138, USA.

1986-1995

Among adults with aged 35-54 yr, Standardised Mortality Ratio (SMRs):

All cancer 3.1

Breast cancer 4.1

Brain cancer 9.2

Pneumonia 120.7

Chronic Obstructive Pulmonary Disease 27.1

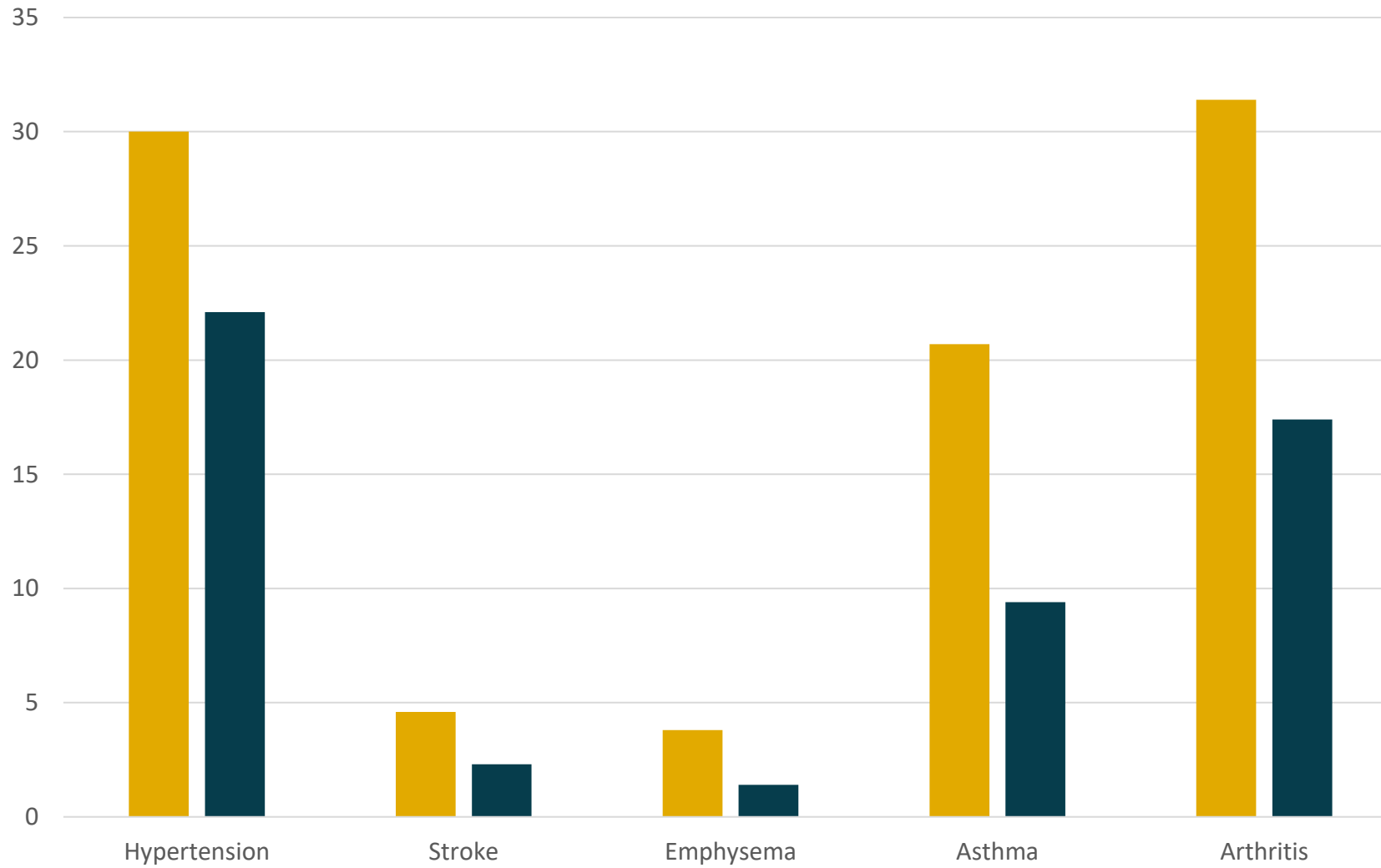
Ischaemic heart disease 3.6

Cerebrovascular disease 2.3

Other heart disease 7.1

Diseases of the circulatory system were the underlying cause of death for 46% of deaths

Prevalence (%)



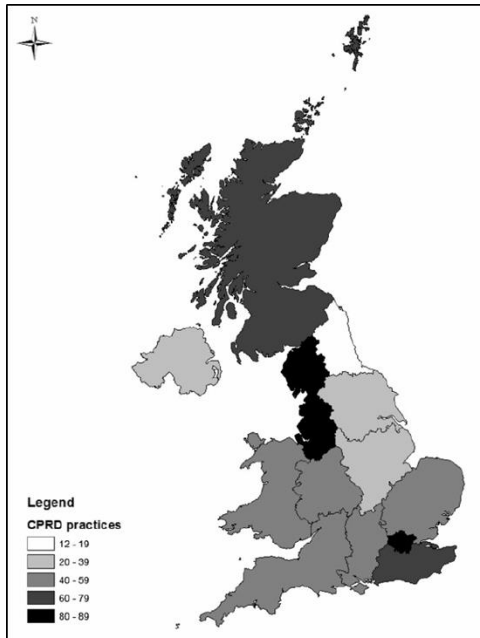
■ Cerebral palsy ■ Without CP

Peterson et al. JAMA 2015

Incidence of non-communicable disease



UK data driving real-world evidence



JAMA Neurology | Original Investigation

Risk of Depression and Anxiety in Adults With Cerebral Palsy

Kimberley J. Smith, PhD; Mark D. Peterson, PhD; Neil E. O'Connell, PhD; Christina Victor, PhD; Silvia Liverani, PhD; Nana Anokye, PhD; Jennifer M. Ryan, PhD

ARTICLE OPEN ACCESS

Noncommunicable disease among adults with cerebral palsy

A matched cohort study

Jennifer M. Ryan, PhD, Mark D. Peterson, PhD, Anthony Matthews, MSc, Nicola Ryan, MB BCH BAO, Kimberley J. Smith, PhD, Neil E. O'Connell, PhD, Silvia Liverani, PhD, Nana Anokye, PhD, Christina Victor, PhD, and Elizabeth Allen, PhD

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Full Length Article

Incidence of osteoarthritis, osteoporosis and inflammatory musculoskeletal diseases in adults with cerebral palsy: A population-based cohort study

Neil E. O'Connell^{a,*}, Kimberley J. Smith^b, Mark D. Peterson^c, Nicola Ryan^{d,e}, Silvia Liverani^f, Nana Anokye^a, Christina Victor^a, Jennifer M. Ryan^{a,g}

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

ORIGINAL ARTICLE

Mortality due to cardiovascular disease, respiratory disease, and cancer in adults with cerebral palsy

JENNIFER M RYAN^{1,2} | MARK D PETERSON³ | NICOLA RYAN^{4,5} | KIMBERLEY J SMITH⁶ | NEIL E O'CONNELL² | SILVIA LIVERANI⁷ | NANA ANOKYE² | CHRISTINA VICTOR² | ELIZABETH ALLEN⁸

Underlying cause of death in adults with CP

Table II: Observed and expected deaths and standardized mortality ratios

Cause of death	Observed/expected deaths	SMR (95% CI)
All causes	142/32.8	4.33 (3.67–5.10)
Malignant neoplasms	13/9.1	1.42 (0.83–2.45)
Diseases of the circulatory system	28/8.8	3.19 (2.20–4.62)
Ischaemic heart disease	9/5.0	1.79 (0.93–3.45)
Cerebrovascular diseases	8/2.3	3.45 (1.73–6.90)
Diseases of the respiratory system	38/2.8	13.59 (9.89–18.67)

SMR, standardized mortality ratios; CI, confidence interval.

Underlying cause of death in adults with CP

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SMR, standardized mortality ratios; CI, confidence interval.

- Underlying cause of 37 deaths (26%) was CP
- Strauss et al. found 30% had potentially uninformative codes such as CP and congenital anomalies
- Landes et al (2023): 58% of deaths (with CP coded somewhere on death certificate), were coded with CP as underlying cause
- If you recode the 37 deaths, diseases of the circulatory system are the most common cause of death

Non-communicable disease risk

Table 2 Incidence rate and unadjusted and adjusted HRs for NCDs comparing patients with CP to patients without CP (n = 6,820)

	Events, n (%)	Person-years, ×1,000	Incidence, per 1,000 person-y	Unadjusted HR (95% CI)	p Value	Adjusted HR ^a (95% CI)	p Value
Cancer							
CP	15 (0.88)	14.5	1.03	0.99 (0.55–1.78)	0.980	1.35 (0.71–2.56)	0.362
Non-CP	83 (1.62)	56.4	1.47	1		1	
Type 2 diabetes mellitus							
CP	47 (2.76)	14.4	3.26	0.89 (0.64–1.23)	0.481	1.06 (0.71–1.59)	0.774
Non-CP	214 (4.18)	55.4	3.86	1		1	
All cardiovascular disease							
CP	248 (14.6)	13.1	19.0	1.20 (1.03–1.40)	0.021	1.76 (1.48–2.11)	<0.001
Non-CP	815 (15.9)	50.5	16.1	1		1	
Respiratory disease							
CP	215 (12.6)	14.3	15.0	1.74 (1.47–2.06)	<0.001	2.61 (2.14–3.19)	<0.001
Non-CP	650 (12.7)	55.3	11.8	1		1	
Any NCD							
CP	—	—	—	1.20 (1.09–1.32)	<0.001	1.75 (1.58–1.94)	<0.001
Non-CP	—	—	—	1		1	

Abbreviations: CI = confidence interval; CP = cerebral palsy; HR = hazard ratio; NCD = noncommunicable disease.

^aAdjusted for smoking status, alcohol consumption, body mass index, and mean yearly general practitioner consultations.

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^aAdjusted for smoking status, alcohol consumption, body mass index, and mean yearly general practitioner consultations.

	Adjusted HR ^a (95% CI)	p Value
Cardiovascular disease		
Heart failure		
CP	2.62 (1.51–4.52)	0.001
Non-CP	1	
Hypertensive disease		
CP	1.64 (1.34–2.01)	<0.001
Non-CP	1	
Ischemic heart disease		
CP	2.32 (1.45–3.71)	<0.001
Non-CP	1	
Cerebrovascular disease		
CP	5.53 (3.04–10.06)	<0.001
Non-CP	1	
Other heart diseases		
CP	1.07 (0.66–1.71)	0.790
Non-CP	1	
Respiratory disease		
COPD		
CP	1.34 (0.89–2.02)	0.165
Non-CP	1	
Asthma		
CP	2.24 (1.82–2.76)	<0.001
Non-CP	1	

Bone and joint disorders

Adults with CP in the United Kingdom have higher risk of:

- Osteoarthritis (HR 1.54, 95% CI 1.17 to 2.02)
- Osteoporosis (HR 6.19, 95% CI 3.37 to 11.39)

But not of inflammatory musculoskeletal diseases (HR 0.89, 95% CI 0.45 to 1.75)

Adults with CP in the United States:

- Higher prevalence of all cause fracture (6.3% vs 2.7%)
- More likely to have a fracture after adjusting for cardiometabolic disease and osteoporosis (OR 2.0, 95% CI 1.8 to 2.2)

Mental and cognitive disorders

Adults with CP in the UK have

- Higher risk of depression (HR 1.28, 95% CI 1.09-1.51)
- Higher risk of anxiety (HR 1.38, 95% CI 1.15-1.64)
- Higher risk of dementia (HR 2.69) but not after adjusting for sensory impairments, epilepsy and ID

Adults with CP or Spina Bifida in the US have a higher risk over 3 years of:

- Any psychological disorder (HR 1.60, 95% CI 1.55-1.65)
- Insomnia, adjustment disorders, anxiety disorders, PTSD, dementias, mood disorders, personality disorders, substance-related disorders (HR range from 1.32 to 2.70)

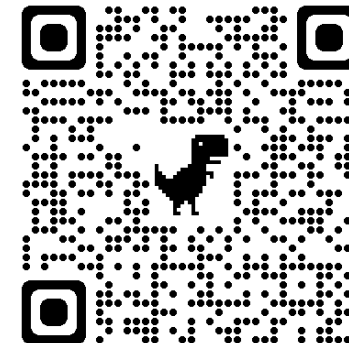
But not alcohol-related disorders

Prevalence and incidence of chronic conditions among adults with cerebral palsy: A systematic review and meta-analysis

Jennifer M. Ryan¹  | Fatemah Albairami^{2,3} | Thomas Hamilton⁴ | Nigel Cope⁵ |
Noor Amirah Amirmudin⁶ | Manjula Manikandan¹  | Cherry Kilbride³ |
Valerie L. Stevenson⁷ | Emma Livingstone⁸ | Jennifer Fortune¹

Aim

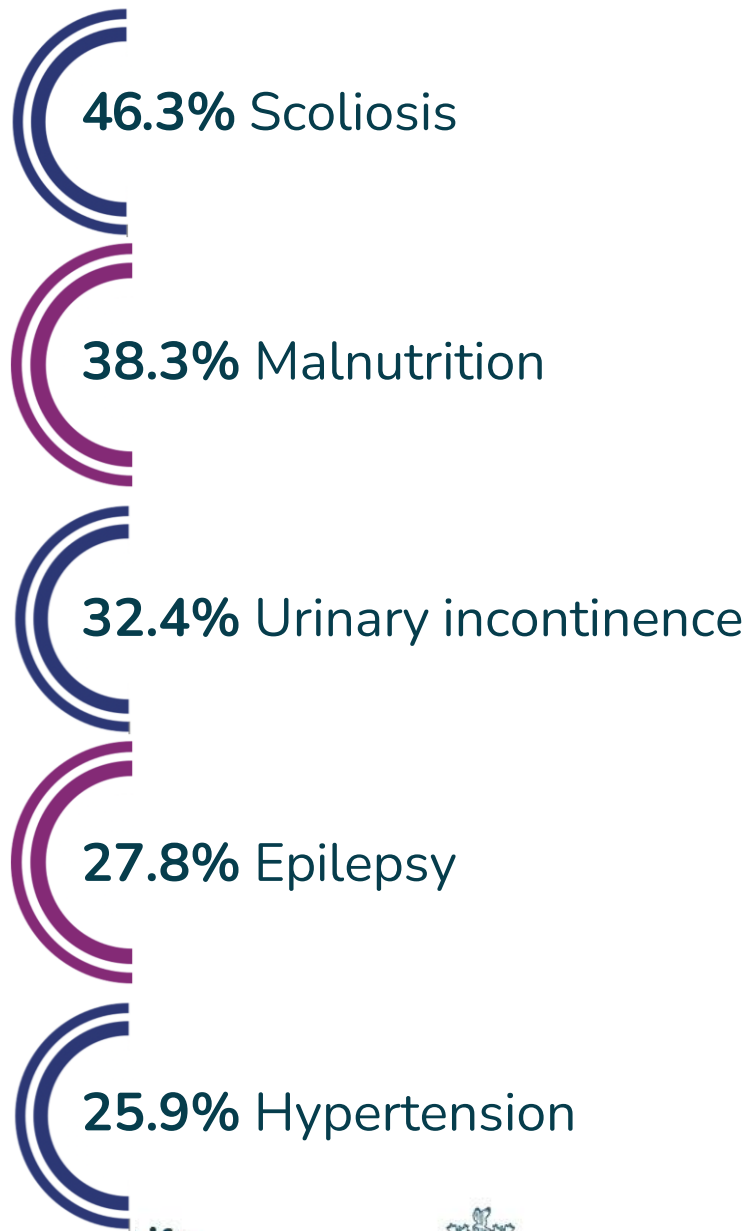
- Assess the prevalence and incidence of chronic conditions among adults with CP
- Compare the prevalence and incidence of chronic conditions between adults with and without CP



- United States (52%)
- Netherlands
- Republic of Korea
- Sweden
- United Kingdom
- Canada
- Italy
- Japan
- Turkey
- Australia, Bosnia, Brazil, France, Iraq, Ireland, Norway, Spain, Taiwan



Prevalence studies (n=65)
Between 22 and 154,219 people per study
25% considered "high quality"





Epilepsy

Hypertension

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Asthma

Depression

Anxiety

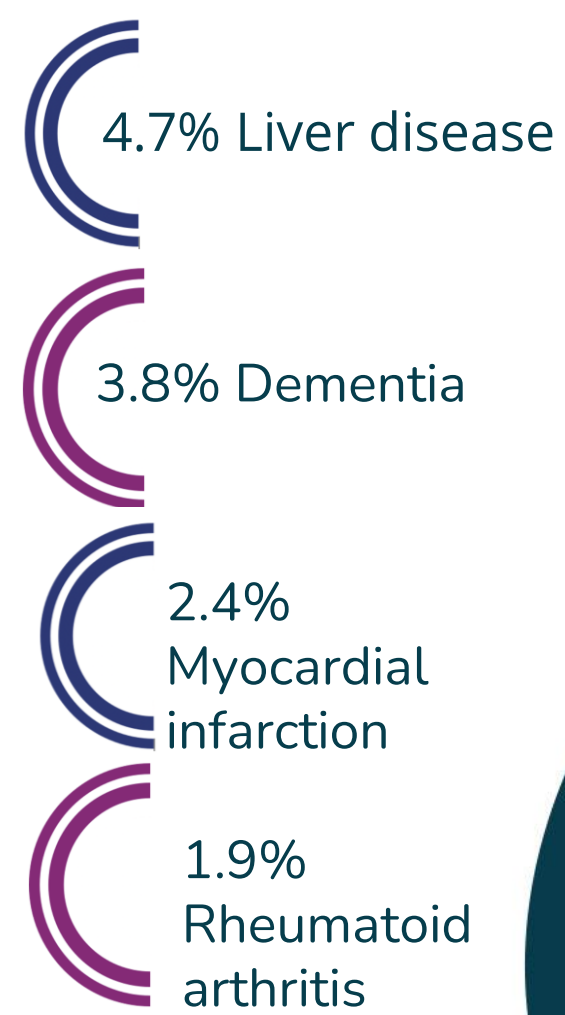
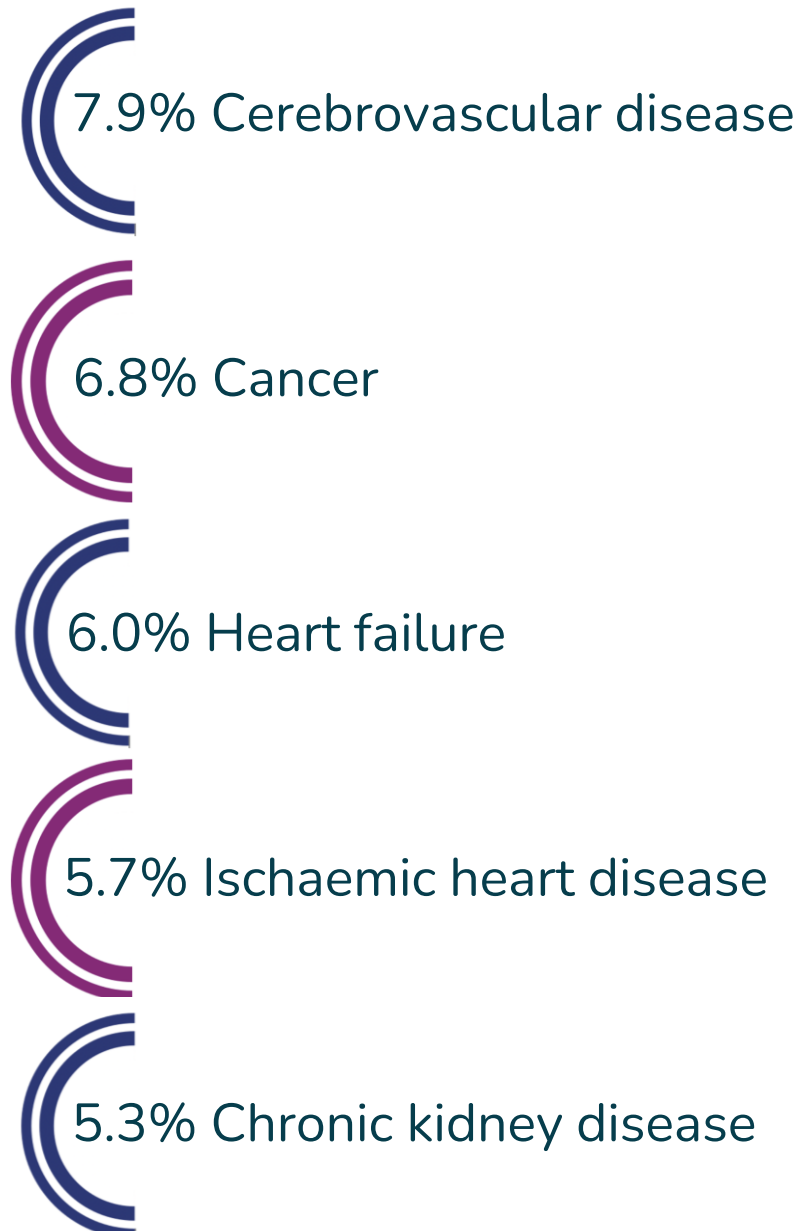
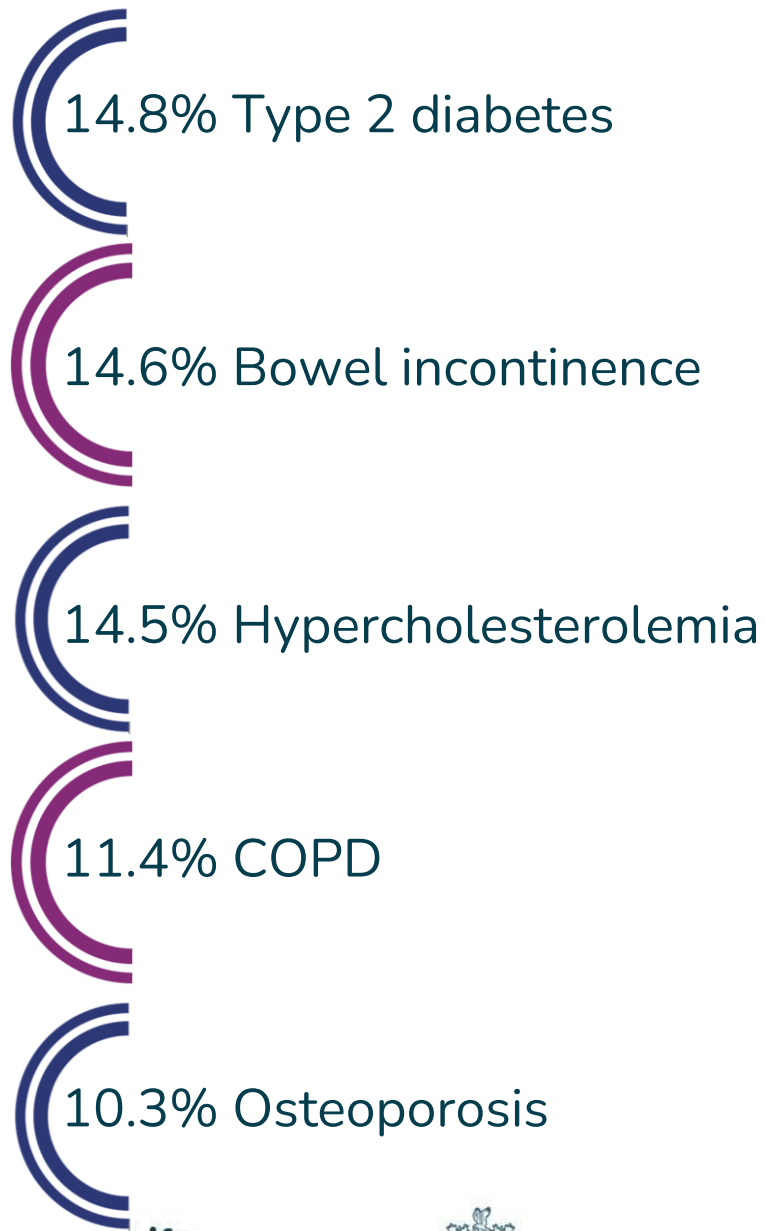
*Direct comparison to adults
without CP



Underweight

Osteoarthritis





Type 2 diabetes



Hypercholesterolemia



Osteoporosis

Cerebrovascular disease

Cancer



Ischaemic heart disease

Chronic kidney disease

Liver disease



*Direct comparison to adults
without CP



GAPS IN OUR KNOWLEDGE

Feeding and eating disorders

Obsessive compulsive disorder

Sleep apnoea

Peripheral vascular disease

Chronic sinusitis

Eczema

Psoriasis

Endometriosis

Menstrual disorders

Prostate disorders

Cataract

Glaucoma

What do adults with CP report?

Systematic review (van Gorp et al, 2020)

65.1% (95% CI 55.1% to 74.5%) of adults with CP reported pain

56.2% (95% CI 37.0% to 74.5%) perceived a decline in mobility over time

Survey of 162 adults with CP in the UK and Ireland

- 78% reported experiencing pain for more than 3 months
- 83% reported a decline in mobility since turning 18 years

What do adults with CP report?

- Adults with CP in the UK experience **6 times as many falls** as adults without CP (HR: 5.83, 95% CI 4.84 to 7.02)

Survey of 162 adults with CP in the UK and Ireland

- 78% reported at least 1 fall in the past year; 24% >10 falls

What healthcare do adults with CP use?

Medical services

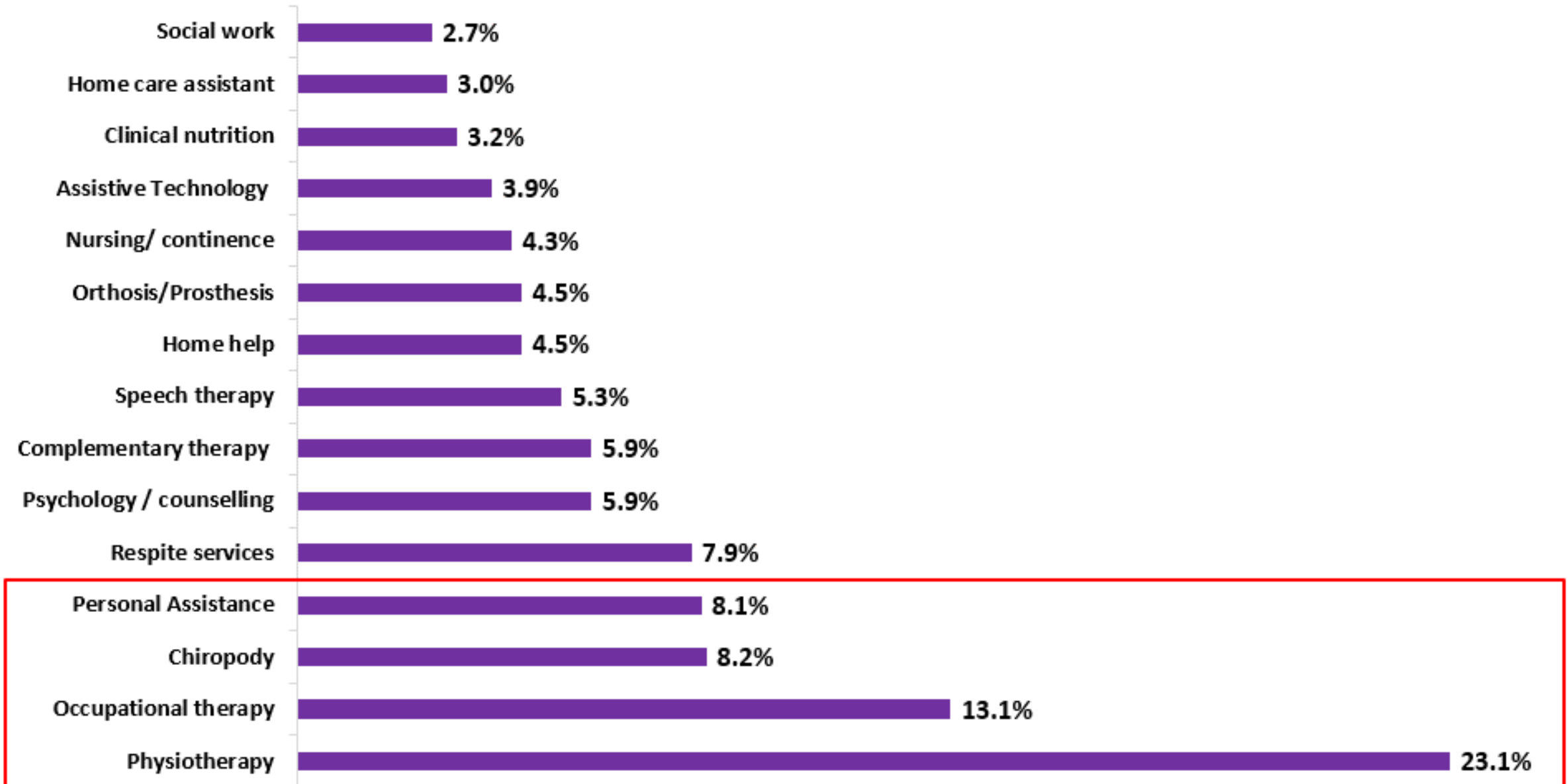
During 12-month period	% adults
• Admitted to hospital	33% (95% CI 23-44%)
• Emergency department visit	28% (95% CI 17-40%)
• General Practitioner visit	84% (95% CI 78-90%)
• Neurologist visit	11% (95% CI 2-20%)
• Orthopaedic surgeon visit	16% (95% CI 6-26%)

What healthcare do adults with CP use?

Rehabilitation services

During 12-month period	% adults
• Physiotherapy	44% (95% CI 36-51%)
• Occupational therapy	27% (95% CI 12-41%)
• Speech and language therapy	16% (95% CI 3-28%)
• Psychologist or psychiatrist	11% (95% CI 1-20%)

Unmet needs among adults with CP in Ireland (n=1,268)



Compared to 18-25 year olds are:

- 25-34 years
- 35-44 years
- 45- 54 years
- 55-65 years

Less likely to use
→

→
More likely to have
unmet need for

- Physiotherapy,
- Occupational therapy
- Speech and language therapy
- Psychology or counselling
- Assistive technology services

(after adjusting for gender, living arrangements, ID, speech impairment, visual impairment, hearing impairment, epilepsy, wheelchair use)

Rehabilitation following fracture

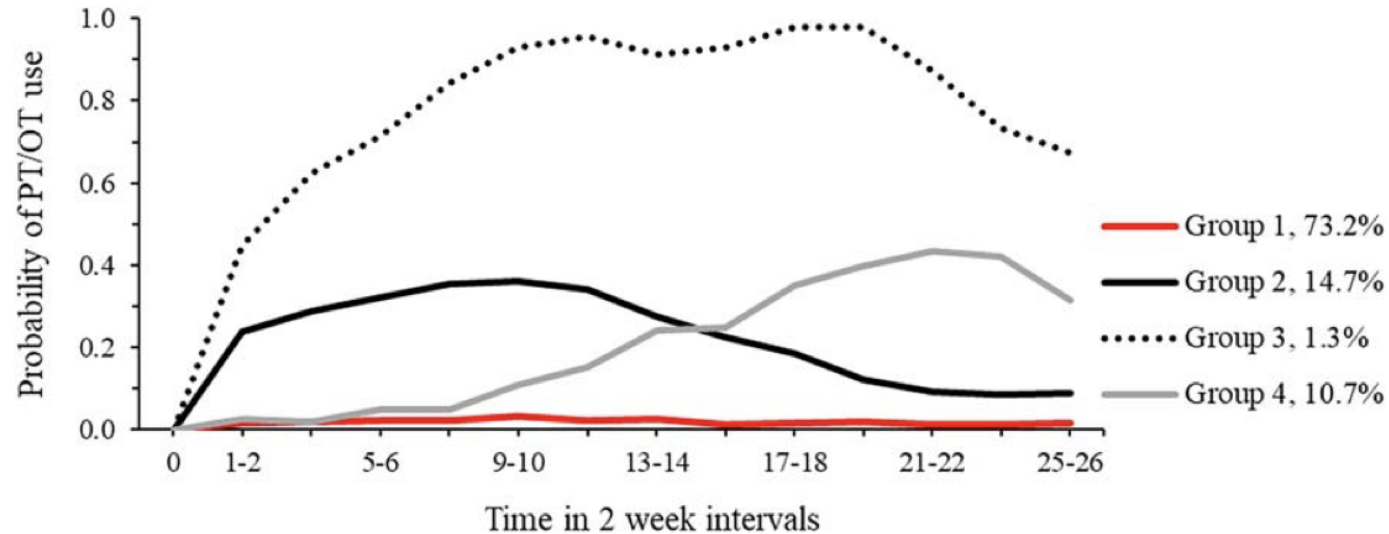


Figure 2. Trajectories for 2-wk probability of physical therapy or occupational therapy (PT/OT) use over 6 mo after fracture among adults with cerebral palsy ($n = 2429$). The percentages represent the proportion of the cohort assigned to each trajectory group.

Rehabilitation following fracture

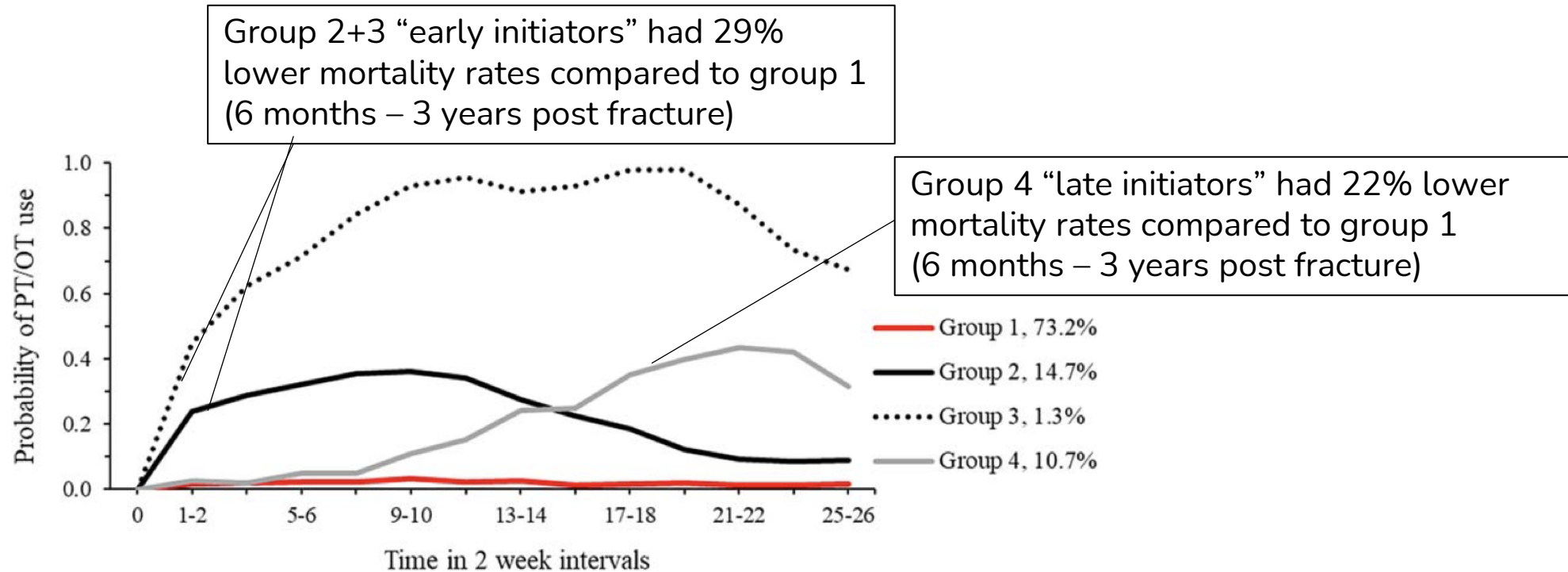


Figure 2. Trajectories for 2-wk probability of physical therapy or occupational therapy (PT/OT) use over 6 mo after fracture among adults with cerebral palsy ($n = 2429$). The percentages represent the proportion of the cohort assigned to each trajectory group.

"I don't actually have any service at the minute. You don't.. there's like nothing really like no specialists in the area like yeah nobody seems to understand like adults, its hard..

Jamie; Adult with CP

"Yeah, like some of them would just say just stop the movements or stop moving and I'd have to explain that while I can't, I can't I don't want to be moving either...Some of them wouldn't have much of an understanding"

Derek; Adult with CP

"The overall caseload..in the department is probably over four hundred and there's three of us."

Magda; Service provider.



Childhood

Adulthood

Pain in childhood

- A systematic review identified between 14% and 76% of children and young adults with CP report pain
- Children and young adults with CP 3 times more likely to be prescribed opioid analgesics compared to those without CP
- Over five years, among a group of adolescents with CP:
 - the prevalence of recurrent pain increased from 67% to 93%
 - number of pain sites, pain intensity, and pain frequency increased

Mental health in children

- Between 4% and 67% of children with CP experience “mental health symptoms”
- Higher prevalence of any mental disorder among adolescents with CP
- Higher prevalence of depression and anxiety

Physical inactivity

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

SYSTEMATIC REVIEW

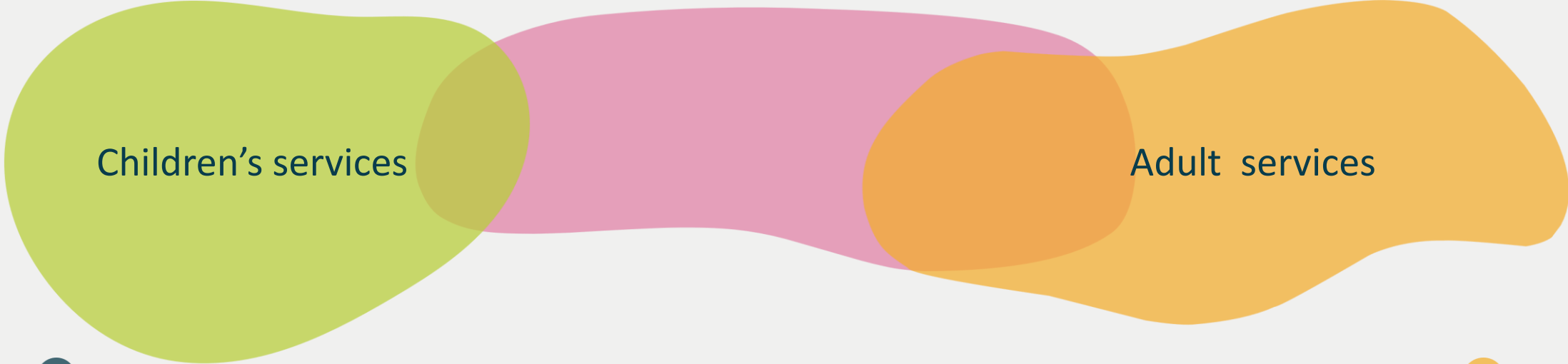
The risk, burden, and management of non-communicable diseases in cerebral palsy: a scoping review

JENNIFER M RYAN^{1,2}  | ELIZABETH ALLEN³ | JOHN GORMLEY⁴ | EDWARD A HURVITZ⁵ | MARK D PETERSON⁵

Consistent evidence that:

- Children with CP participate in less physical activity
- Spend more time in sedentary behaviour

Some evidence that children with CP are less likely to meet physical activity recommendations



Family centred



Adult centred



Friendly supportive



Impersonal, anonymous



Long relationships



New changing providers



Family centred

“their mission statement is to **treat the child and family**. So you're not surplus to requirements, **you're part of the process** in all aspects” Parent

Children's services

Adults' services

“it's very clear for medical people to say look **I am dealing only with this person**, this patient and that can be hard for the parents” Health professional

Adult centred

Children's services

Friendly supportive

"everybody was **so nice to you**. And there was never anybody disappointed if you didn't do something right" Young person

Adults' services

"All of a sudden you **just become a number**. They don't know anything about her"
Parent

Impersonal, anonymous

Long relationships

I've only had, ever had two physiotherapists in there. I know them all and they all know me really, really well. And it's just; it's quite comforting" Young person

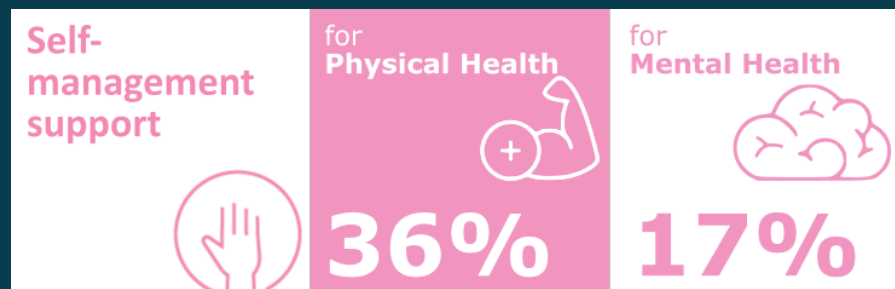
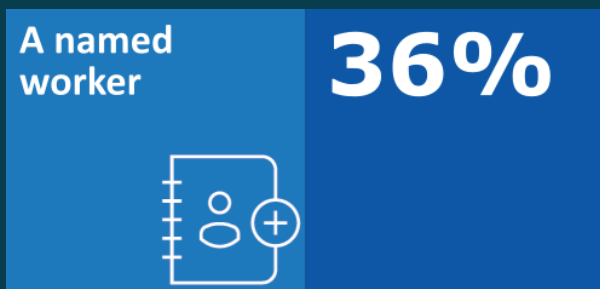
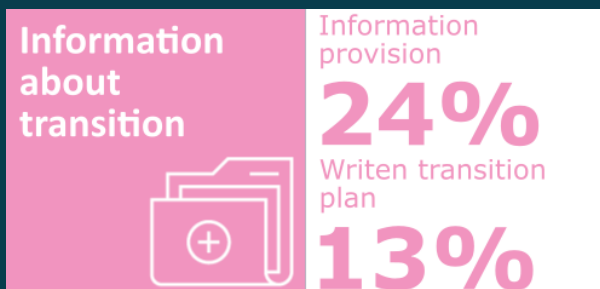
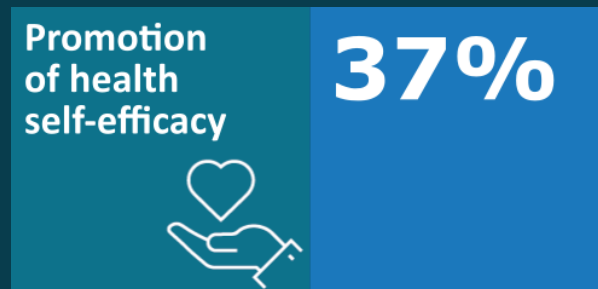
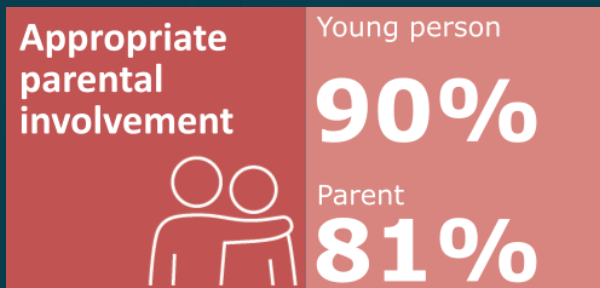
Children's services

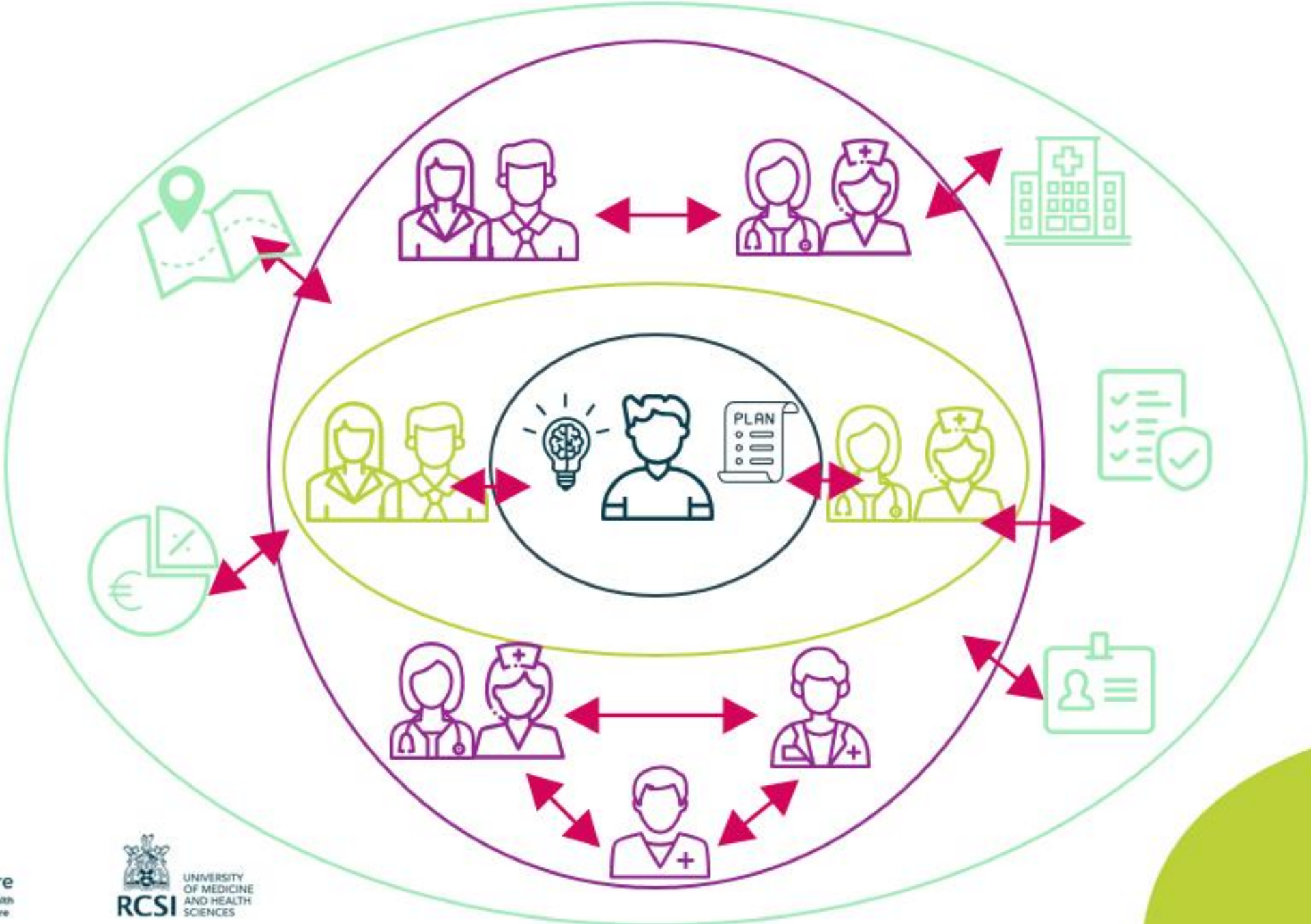
Adults' services

"Nobody is going to come looking for you if you don't present with your needs or you don't articulate what your needs are" Health professional

New changing providers

Young people 16-22 years (n=75)





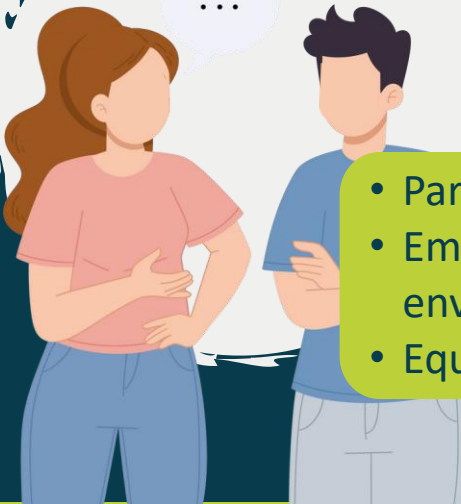
Pre-transition

“Just generally, like I don’t have much information about like **the effect that cerebral palsy would have on my health when I’m older**. Like I have no idea, I don’t know” Young person

Post-transition

“I kind of ignored it as a kid. I still do now, but I suppose **I’m kind of more learning to accept that I have it**. But even like learning what type of cerebral palsy I have and what does that mean” Young person

Developmental transitions



- Parent guidance and support
- Empowering home environments
- Equal opportunities



- Effective communication and personalized information
- Tailored to individual interests and strengths



- Difficulty letting go
- Emotional barriers to education



- Too much support
- Do not actively educate
- Insufficient time and space



What can support a lifecourse approach to CP?



Improved communication and collaboration between people with CP, families and health professionals



Enhanced awareness of challenges all stakeholders face



Support for families to adapt to child's growing independence



Peer support programmes for young people



Ongoing information to people with CP: services, health professional roles, condition



Health professionals willing to learn about CP and work with adults



Multi-disciplinary teams to provide review and proactive care



Thank you

www.CP-LifeCentre.ie



Dr Jenny Fortune



Dr Manjula Manikandan

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