

Observing TBI post-acute care pathways: what can we gain from it?

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- Severe TBI and care pathways
- Objectives and issues of care pathway research

➤ Understanding what happens

- Access to inpatient rehabilitation
- Late care utilization
- Patient follow-up

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➤ Comparing different systems of care

- The Paris-Turku project
- The Center-TBI study

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Why *severe* Traumatic Brain Injuries (TBI) ?

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- Severe TBI
 - Traditional definition → initial GCS ≤ 8
 - New suggested definition → Patient requiring ICU care¹
- 23 / 100 000 inhab / year in Europe²
- Unfavorable outcome: 51%-66%³
- Highest care needs
 - Organization of care pathway critical

1. CENTER-TBI study. <https://www.center-tbi.eu/>

2. Tagliaferri et al. Review of brain injury epidemiology in Europe. *Acta Neurochir Wien* 2006

3. Roozenbeek et al. Changing patterns in the epidemiology of TBI. *Nat Rev Neur* 2013

Post-acute care - definitions

Introduction

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- **Inpatient Rehabilitation (IR)** (*= hospitalized patient*) vs **Outpatient Rehabilitation (OR)** (*= day hospital, ambulatory, home-based care*)
- **Acute Care** = Intensive care (ICU) / neurosurgical care / other medical or surgical wards
 - **Acute rehabilitation** = rehabilitation that takes place in this phase
- **Post-acute care** = all that happens after the acute care¹
 - Includes IR, nursing homes, OR, home services...

(Other definition²)

- Sub-acute care = inpatient rehabilitation
- Post-acute care = everything which happens after home discharge. Includes outpatient rehabilitation)

1. Buntin. Access to postacute rehabilitation. Arch. Phys. Med. Rehabil. 2007

2. Mazaux et al. Rehabilitation after traumatic brain injury in adults. Disabil. Rehabil. 1998

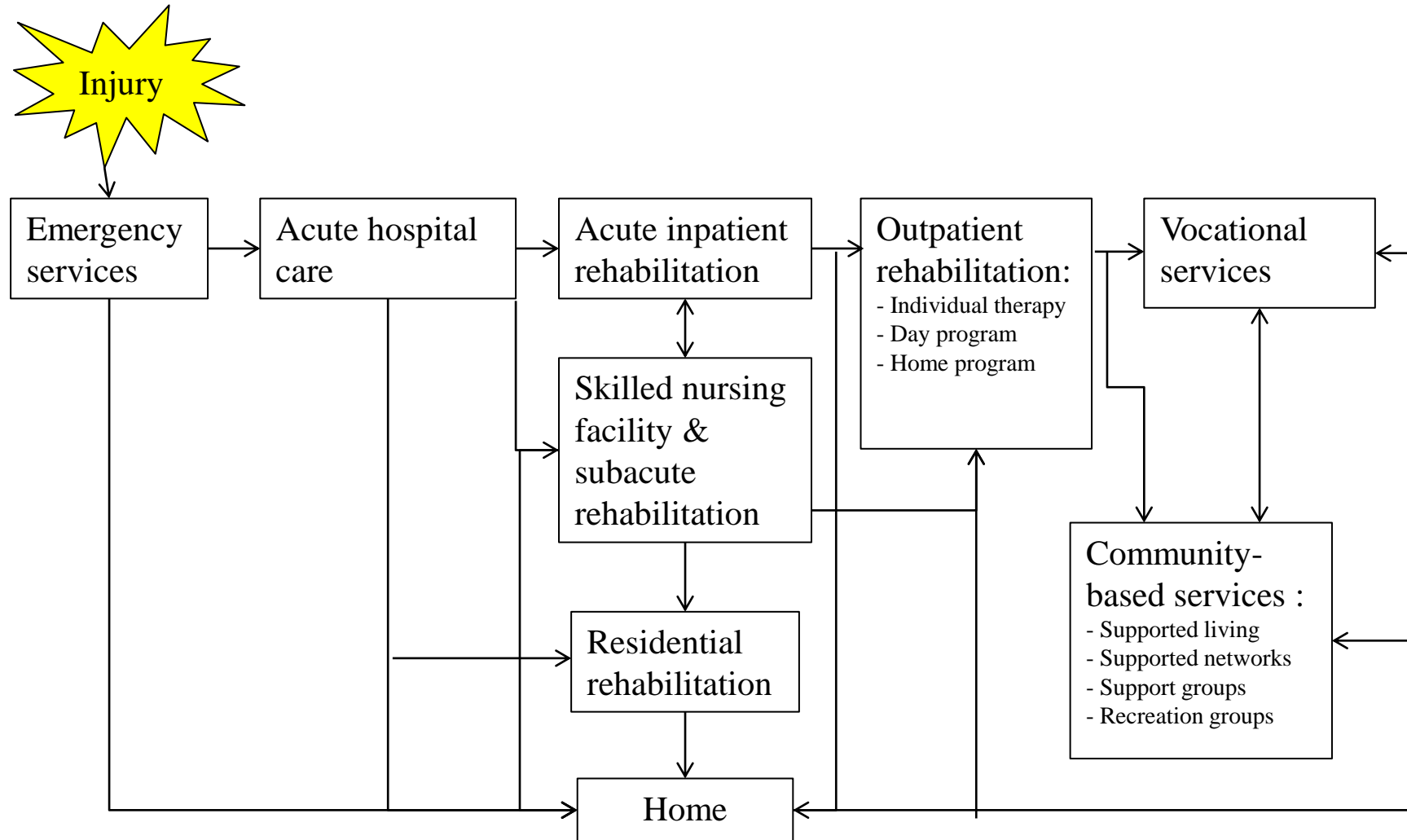
Post-acute care pathways in TBI

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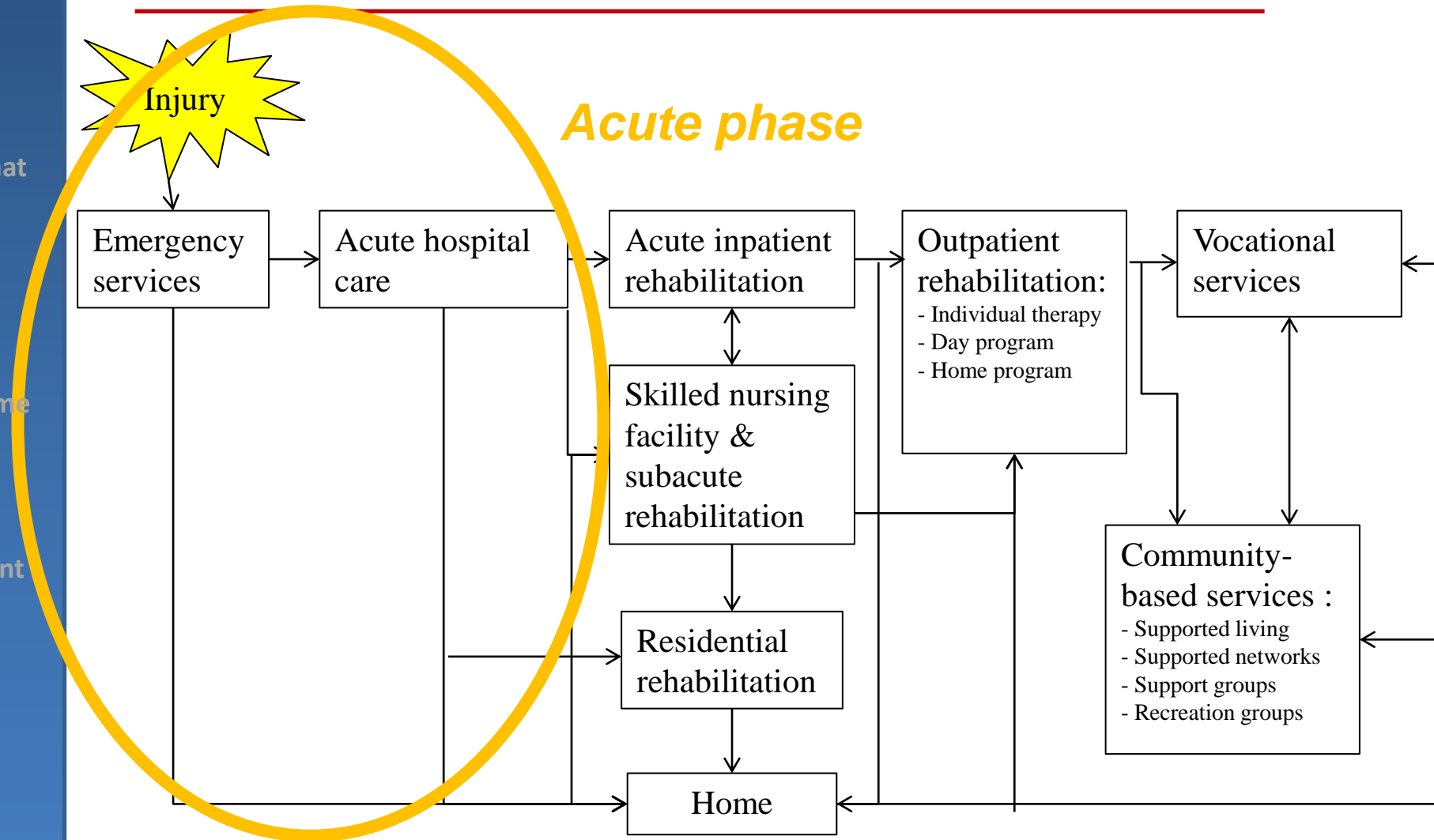
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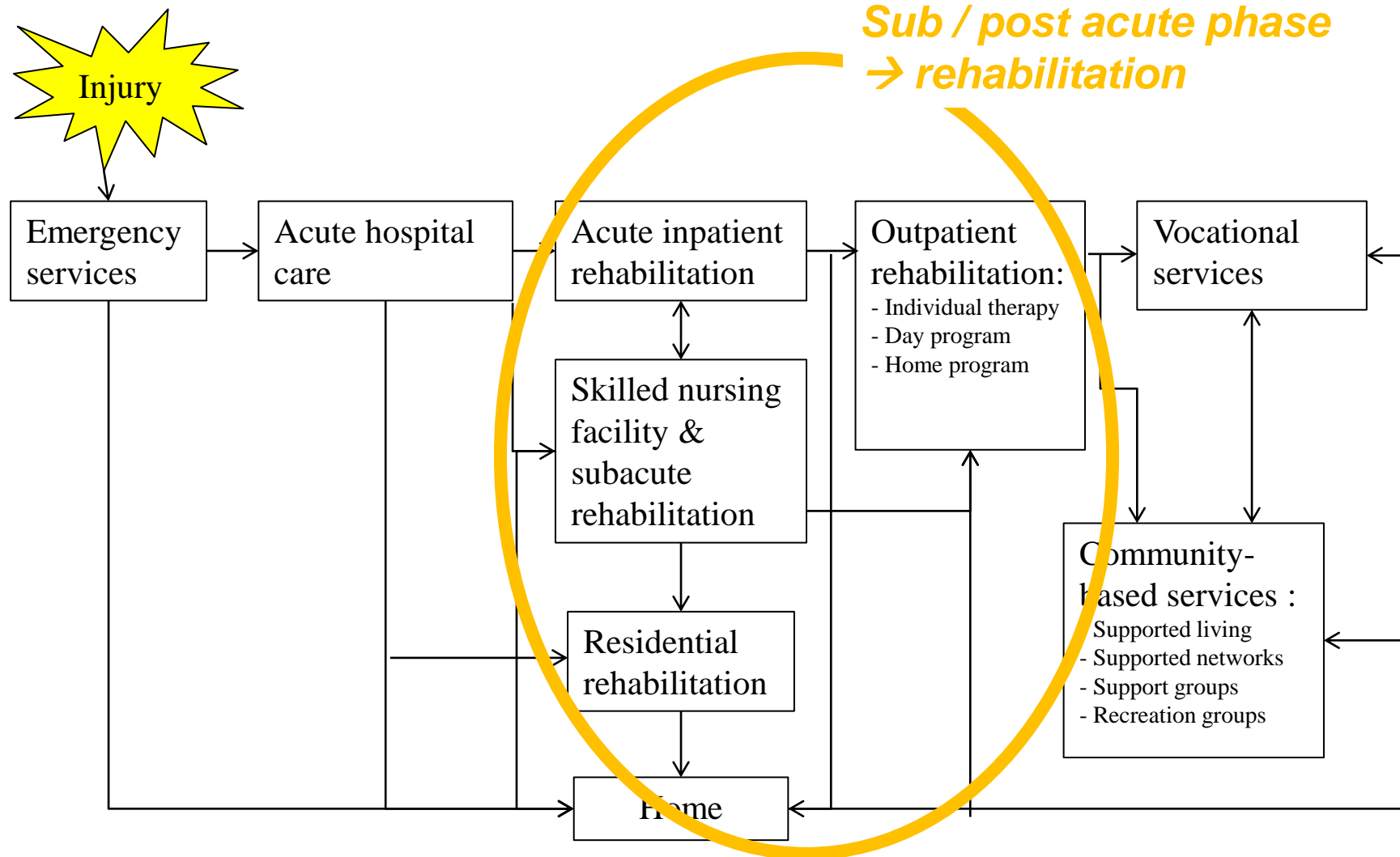
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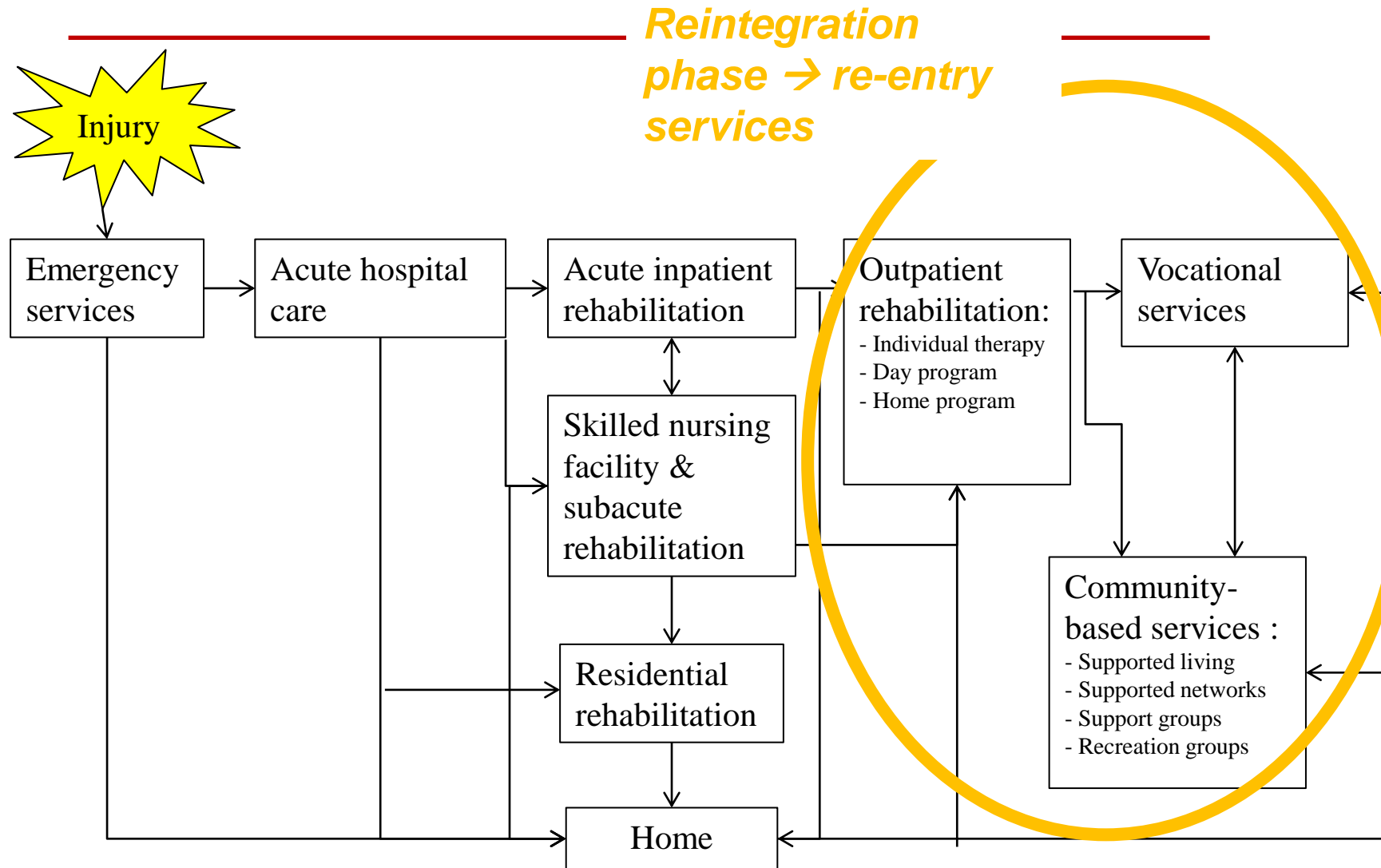
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Evidence for rehabilitation in TBI

RCT or observational studies

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- *Turner-Stokes et al., Cochrane 2005*
 - **Rehabilitation** improves functional outcome
 - *Turner-Stokes et al., J Rehabil Med 2008*
 - **Early rehabilitation** leads to reduced lengths of stay and improved outcomes
 - Rehabilitation leads to greater **functional gains**
 - Rehabilitation leads to **reduced needs for support**
 - *Cicerone et al., Arch Phys Med Rehabil 2011*
 - Benefit of **cognitive rehabilitation**
- ➔ But little information on **how to deliver** post-acute care (setting? contents? critical quality aspects?)
- ➔ Guidelines mostly based on **expert opinions**

« TBI pathways of care »

French PMR Society, 2012

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- French recommendations (2004) → access to IR for all patients with severe TBI
- In 2011 - 2012: « PMR care pathways »¹
 - Expert opinion
 - Three main categories of situations according to
 - TBI severity and clinical course
 - Environment and context
 - Subcategories
 - Pathway guidelines for each category / subcategory
 - Settings of care
 - Contents of care

1. Pradat-Diehl et al., *Annals Phys Rehab Med*, 2012

Objectives of research on post-acute care pathways

- Helping to deliver care in the most appropriate way to achieve good patient outcomes
- Which implies
 - Understanding what happens in reality and why
 - Strengths and weaknesses of care pathways
 - How to improve them
 - Finding out which would be the best care pathways

Issues in TBI care pathways research

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1. Patient variability (no two identical situations!)
 - care must be individualized
 - difficult to study on a population scale
2. Variability of evolution
 - needs of care change with time
 - evolution difficult to predict
3. Variability of care contexts
 - how to generalize one's findings?

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Philippe Azouvi



Eleonore Bayen



Claire Jourdan

Understanding what happens



The Severe Traumatic Brain Injury in Paris study (PariS-TBI)

Relating care pathway to outcome



Alexis Ruet



Claire Vallat

Comparing different systems of care



Sylvie Azerad



Emmanuelle Darnoux



Pascale Pradat

The PariS-TBI study

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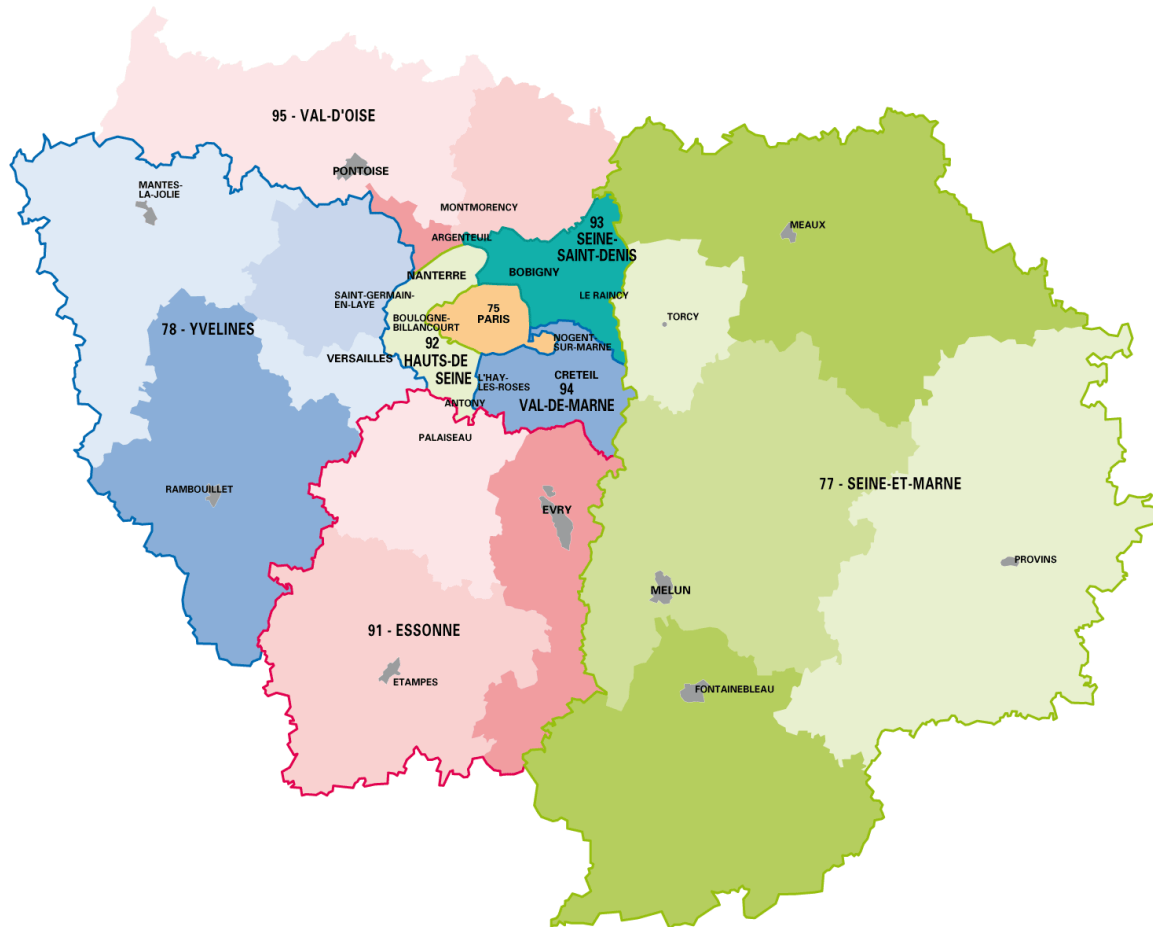
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- Prospective inception cohort study of patients with severe TBI in the Parisian area
- With special emphasis on:
 - Outcome prediction (impairments, activity, participation and quality of life)
 - **Care pathways and health care resource utilization**
 - Informal care (relative's burden)

The Parisian area



- Paris and surrounding districts
- 12 000 km²
- 11.6 million inhabitants
- 92% urban
- 5 level I Trauma Center, mostly in Paris

The PariS-TBI study

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- Inclusion: July 2005-April 2007
 - By mobile emergency services
 - Severe TBI: initial GCS score ≤ 8
 - Accident within the Parisian area
 - Age ≥ 15 years
- 504 patients, 257 acute care survivors
- One-year outcome (telephone interview)
- 4-year outcome (face to face interview)
- 8-year outcome (ongoing)

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PariS-TBI: referral to inpatient rehabilitation

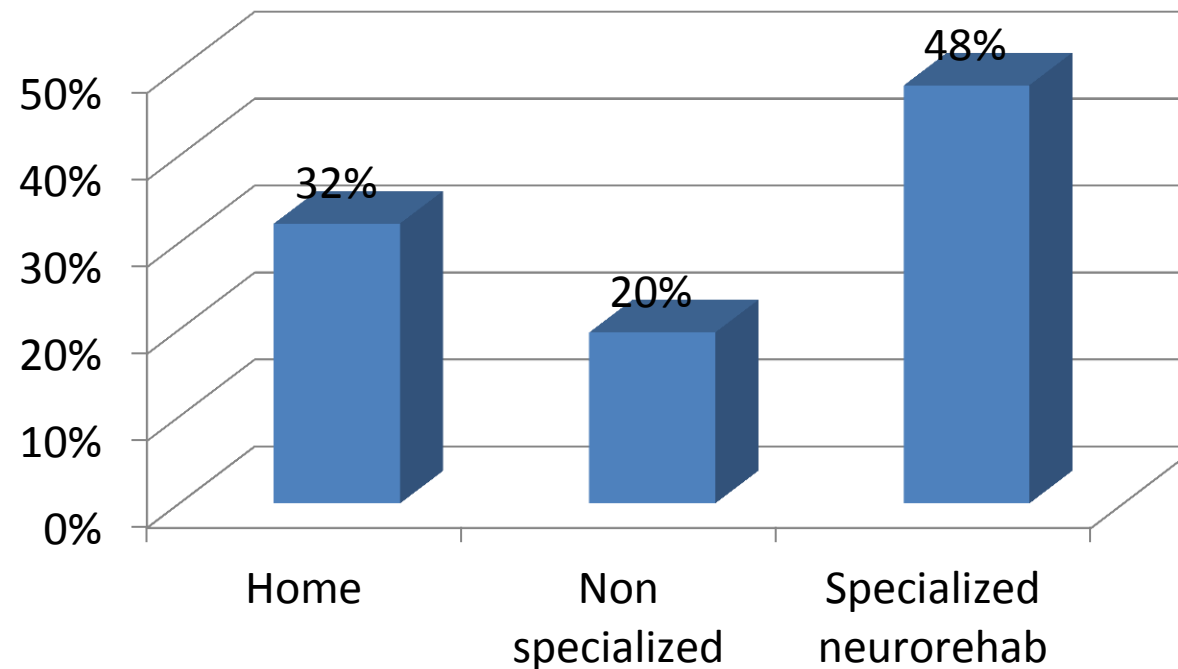
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Referral to Rehabilitation After Severe Traumatic Brain Injury: Results From the PariS-TBI Study

Neurorehabilitation and
Neural Repair
XX(X) 1–10
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DOI: 10.1177/1545968312440744
<http://nnr.sagepub.com>


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Logistic model: rehabilitation vs. home discharge (n=149)

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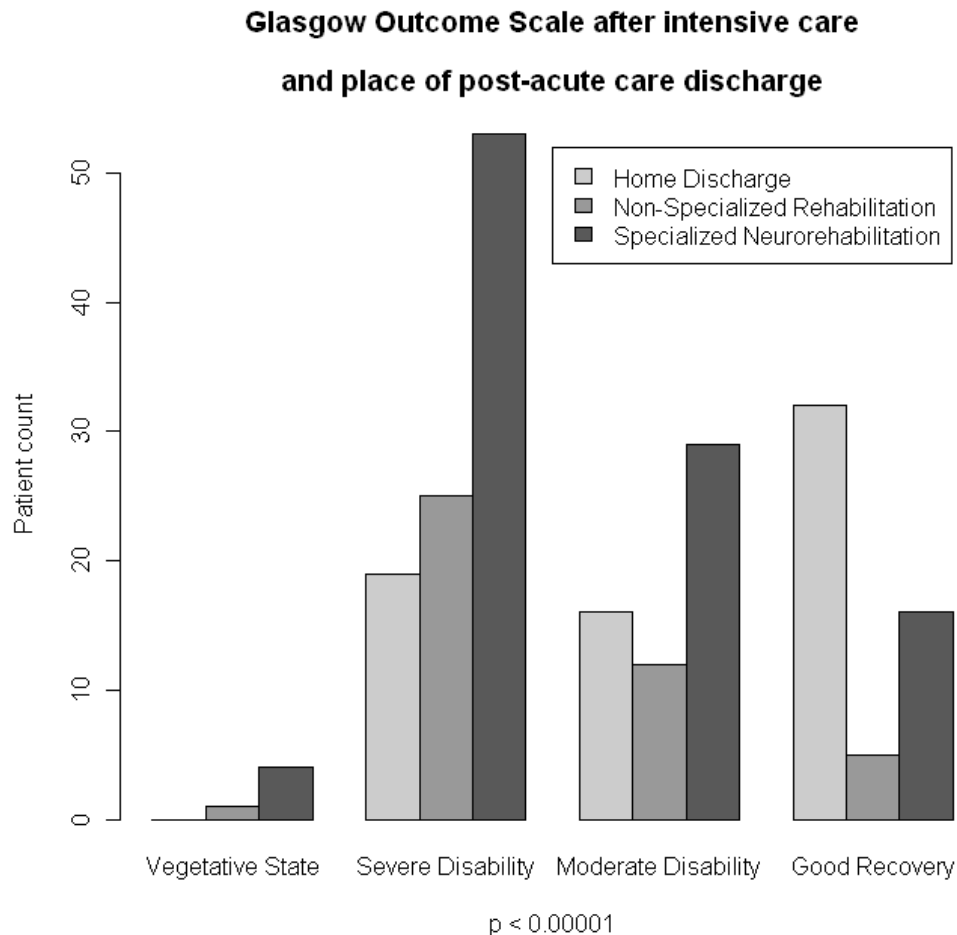
Relating care pathway to outcome

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Variable	Adjusted Odds ratio
Glasgow Coma Scale	0.94 [0.77-1.16]
Time to follow command	1.05 [1.0-1.11]
Disability at discharge from intensive care	0.49 [0.29-0.82] **
Home environment: living alone vs. not	0.49 [0.21-1.17]
Alcohol history: yes	0.32 [0.11-0.93] *
Last unit of acute care: non-specialized medical	0.08 [0.01-0.41] **

Jourdan et al., NNR 2013

Decision of referral to IR and clinical state at the end of ICU



IR seems to be related to need

BUT

- Some severe patients after ICU were not referred to IR later
- acute care clinical evaluation is never enough in TBI

Logistic model: specialised vs. non-specialised rehabilitation (n=136)

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Variable		Adjusted Odds ratio
GCS		0.98 [0.76-1.26]
Age		0.99 [0.95-1.04]
Alcohol abuse		0.35 [0.08-1.62]
Professional level	Higher/lower managers	Reference
	White/blue collar workers	0.16 [0.03-0.85] *
	Self-employed	0.19 [0.01-3.27]
	Non-active	0.14 [0.02-0.92] *
	Retired	0.09 [0.01-0.84] *
	Students	0.35 [0.08-1.62]

Other results – acute and post-acute pathways

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- Causes for discharge home instead of IR?
 - Waiting delays in acute care (16%)
 - Too optimistic prognosis evaluation in acute care
 - Lack of awareness and refusal from patient? 5 patients
- Lengths of stay and delays
 - ICU: 26 +/- 21 days
 - Delays before IR: 58 +/- 60 days (min – max = 12 – 616)
- Number of places of care
 - ICU: 20 centres / IR: 48 centres

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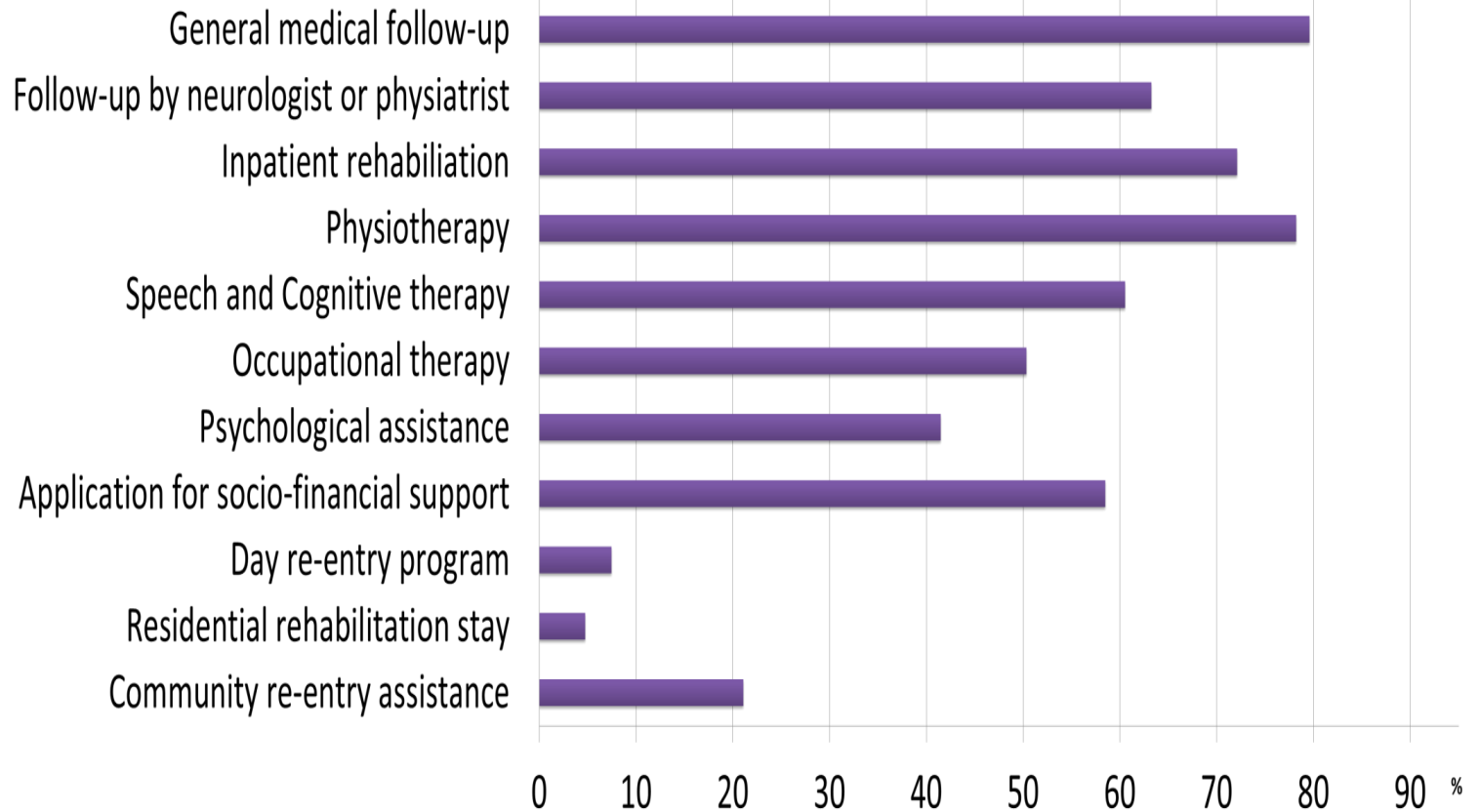
PariS-TBI: utilization of health care resources up to 4 years post-injury

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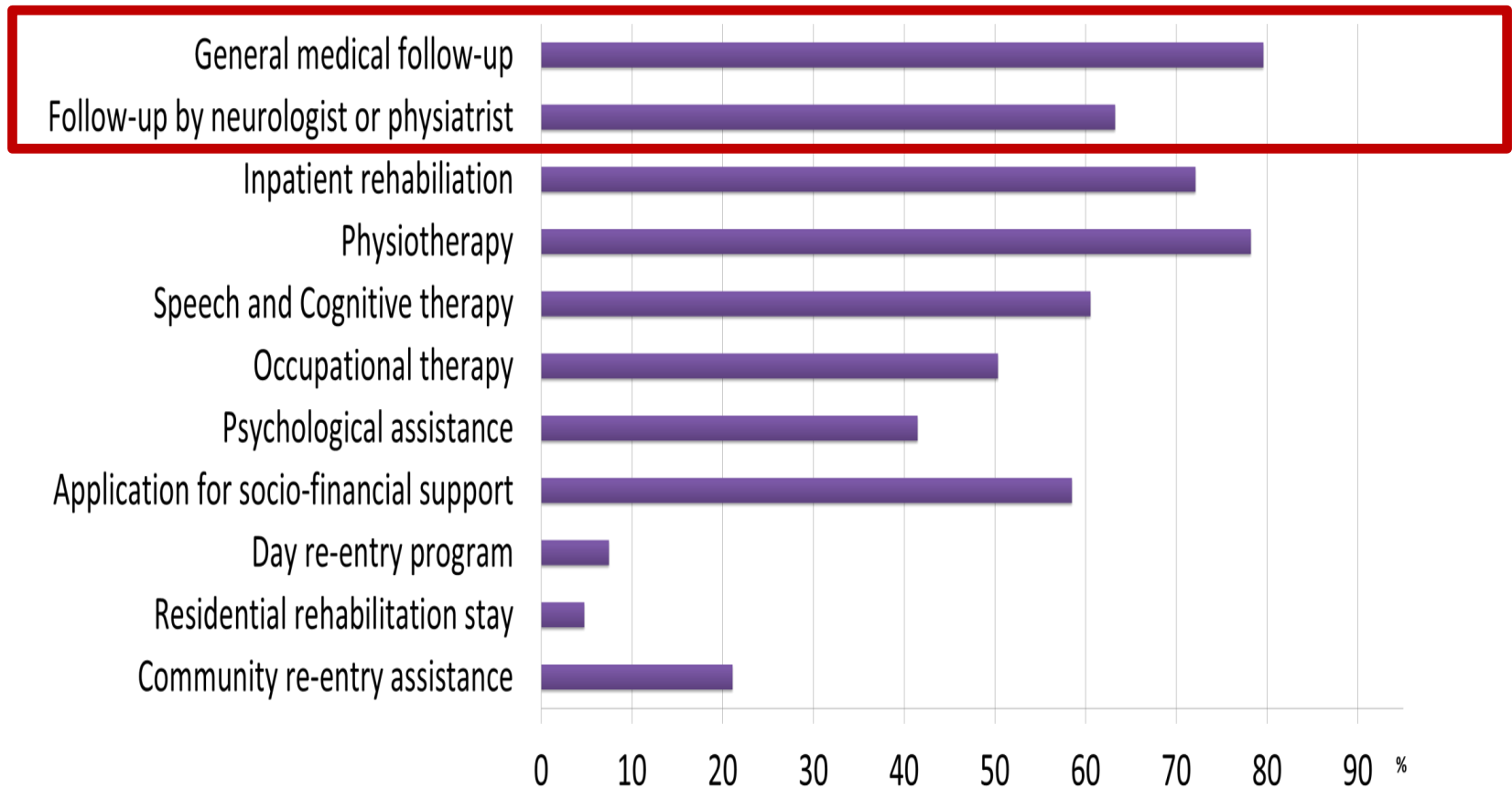
Jourdan et al., Brain Injury, in revision

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**High rates of medical services
... but 63% specialist follow-up only**

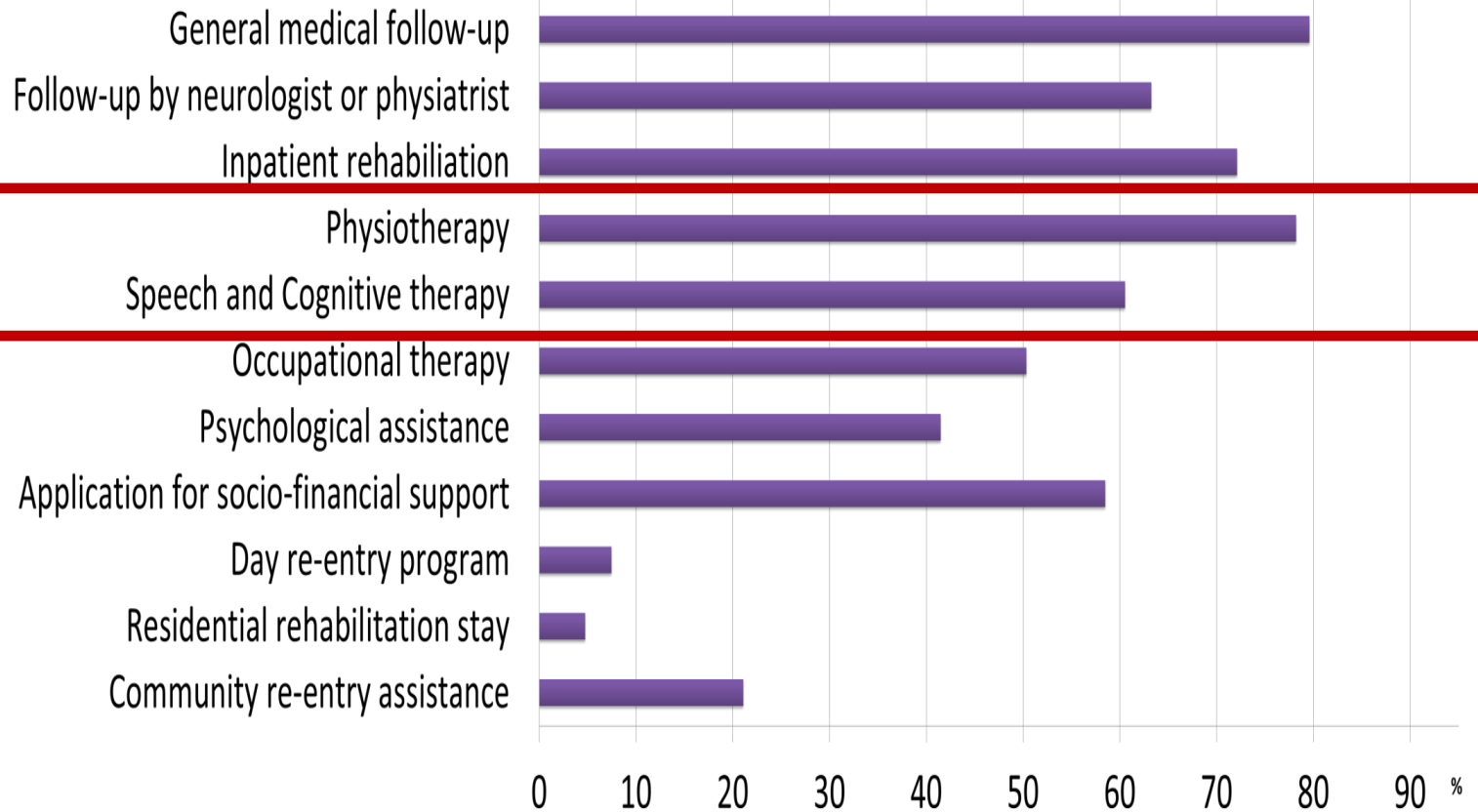
Jourdan et al., Brain Injury, in revision

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High rates of rehabilitation services

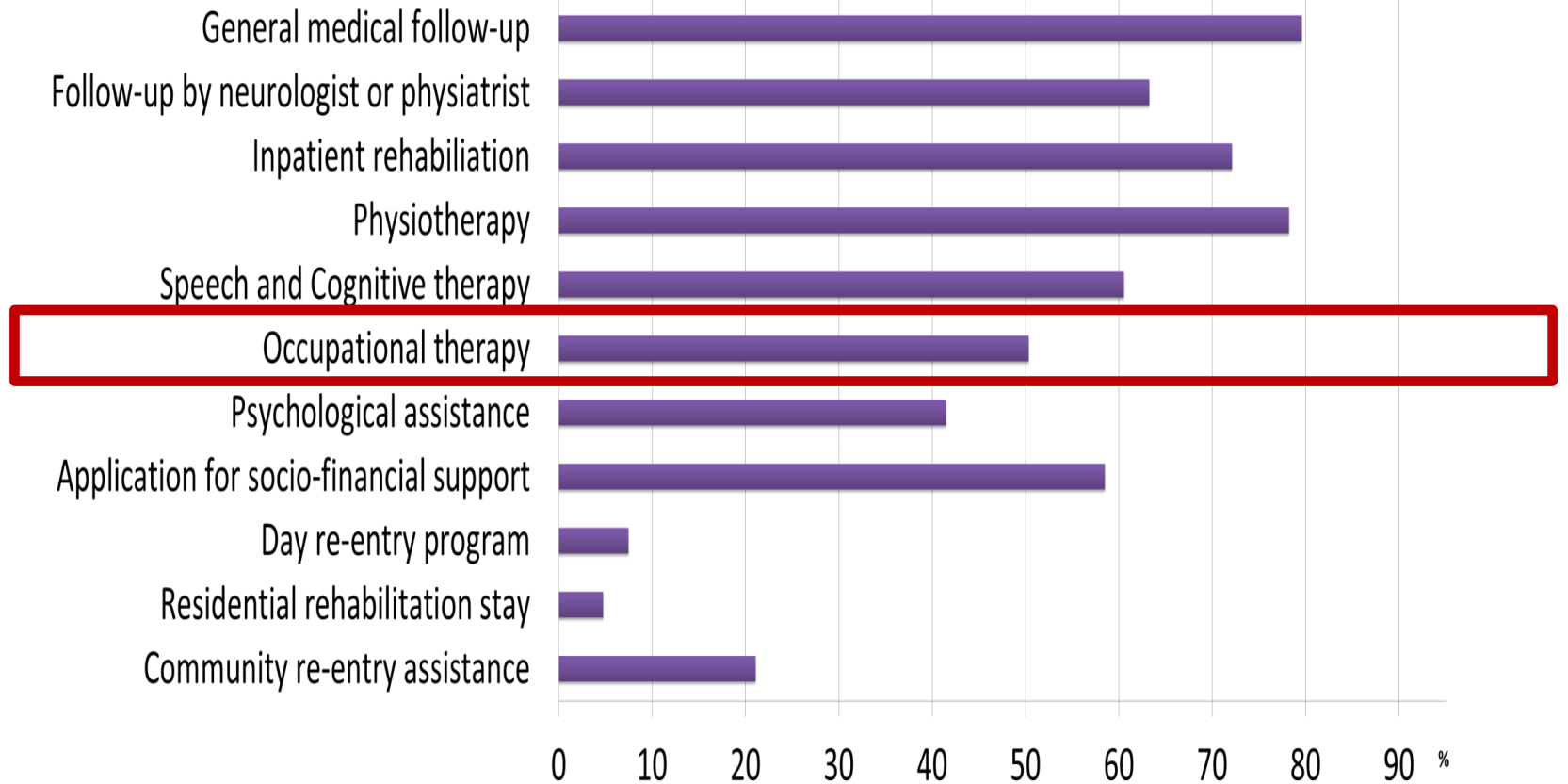
Jourdan et al., Brain Injury, in revision

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**But lower rates of occupational therapy
(not reimbursed as ambulatory care)**

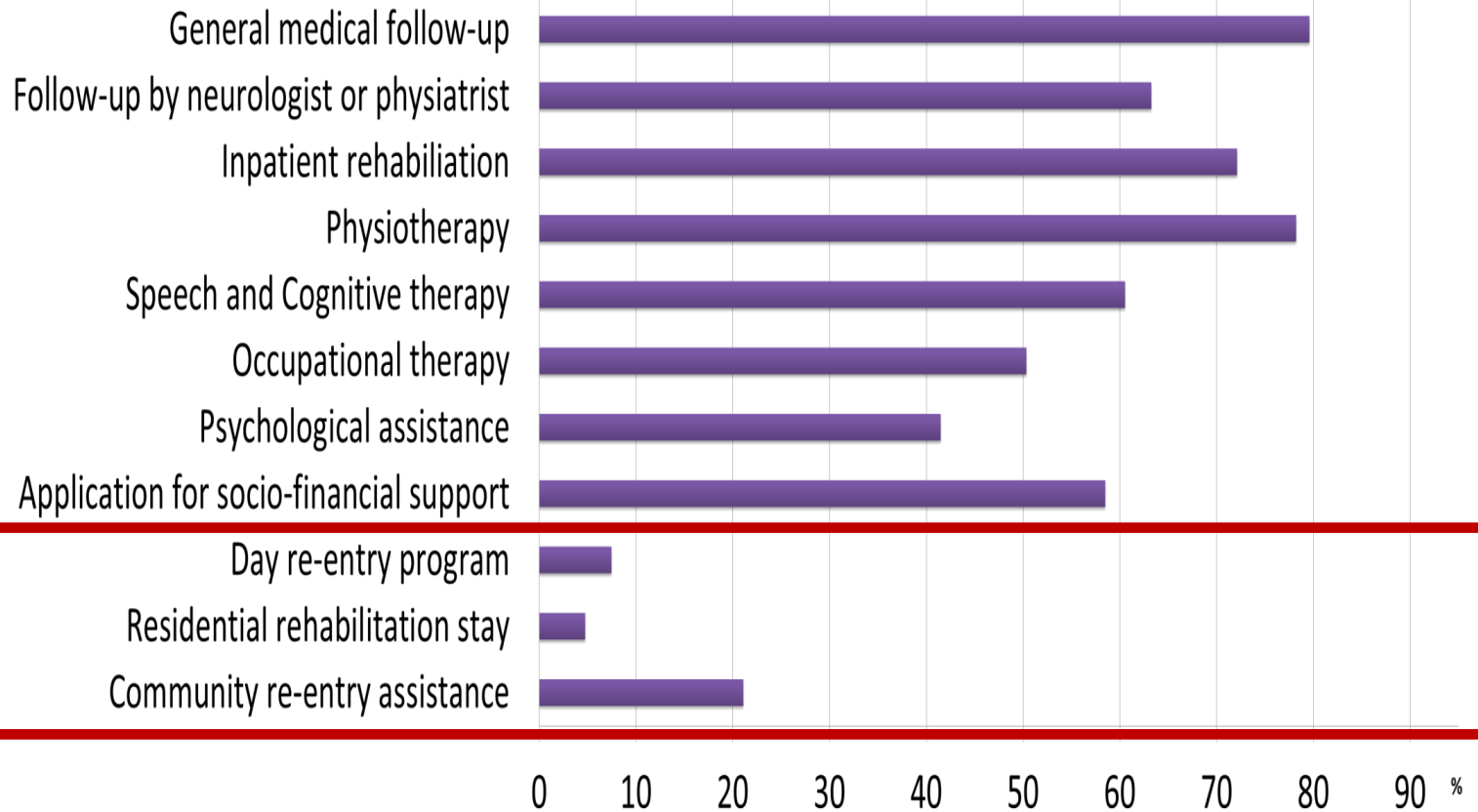
Jourdan et al., Brain Injury, in revision

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Low rates of re-entry services

Jourdan et al., Brain Injury, in revision

Which factors influence late health care utilization (HCU) ?

1. Needs

- ➔ HCU significantly related to
 - TBI severity: main factor
 - specific impairments:
 - Motor impairments → ↗ physiotherapy
 - Pain → ↗ physiotherapy ↗ speech therapy
 - Anxiety and depression → ↗ psychotherapy
 - Speech & language impairments → ↗ speech therapy

Which factors influence health care utilization (HCU) ?

1. Needs

➔ But **no association** between any health service and **cognitive disorders** (DEX, NRS-R scales)

Which factors influence health care utilization (HCU) ?

2. Socio-demographic and geographical factors

- **Rare associations** between provision of services and
 - alcohol history (medical follow-up)
 - isolation (speech therapy)
 - medical density (speech therapy)

Specific patient profile for re-entry services

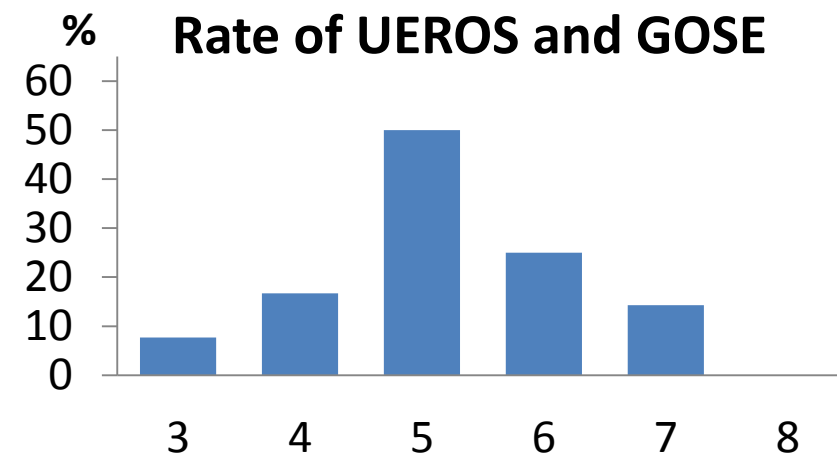
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- Re-entry services provided by UEROS units
- Factors associated with visits with UEROS (23% of patients):
 - younger age
 - independance in ADL
 - intermediate global disability



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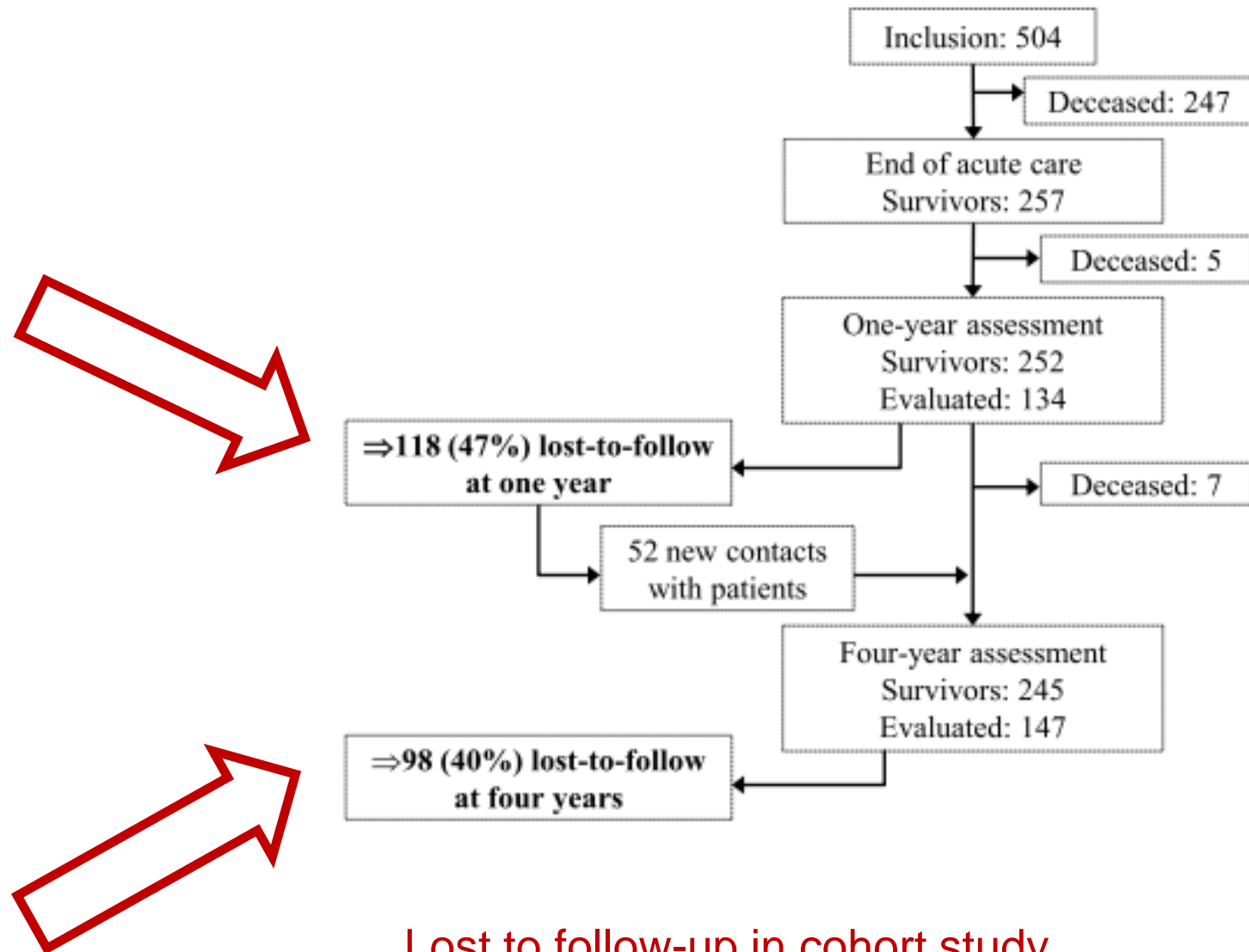
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PariS-TBI: lost to follow-up

Relating care
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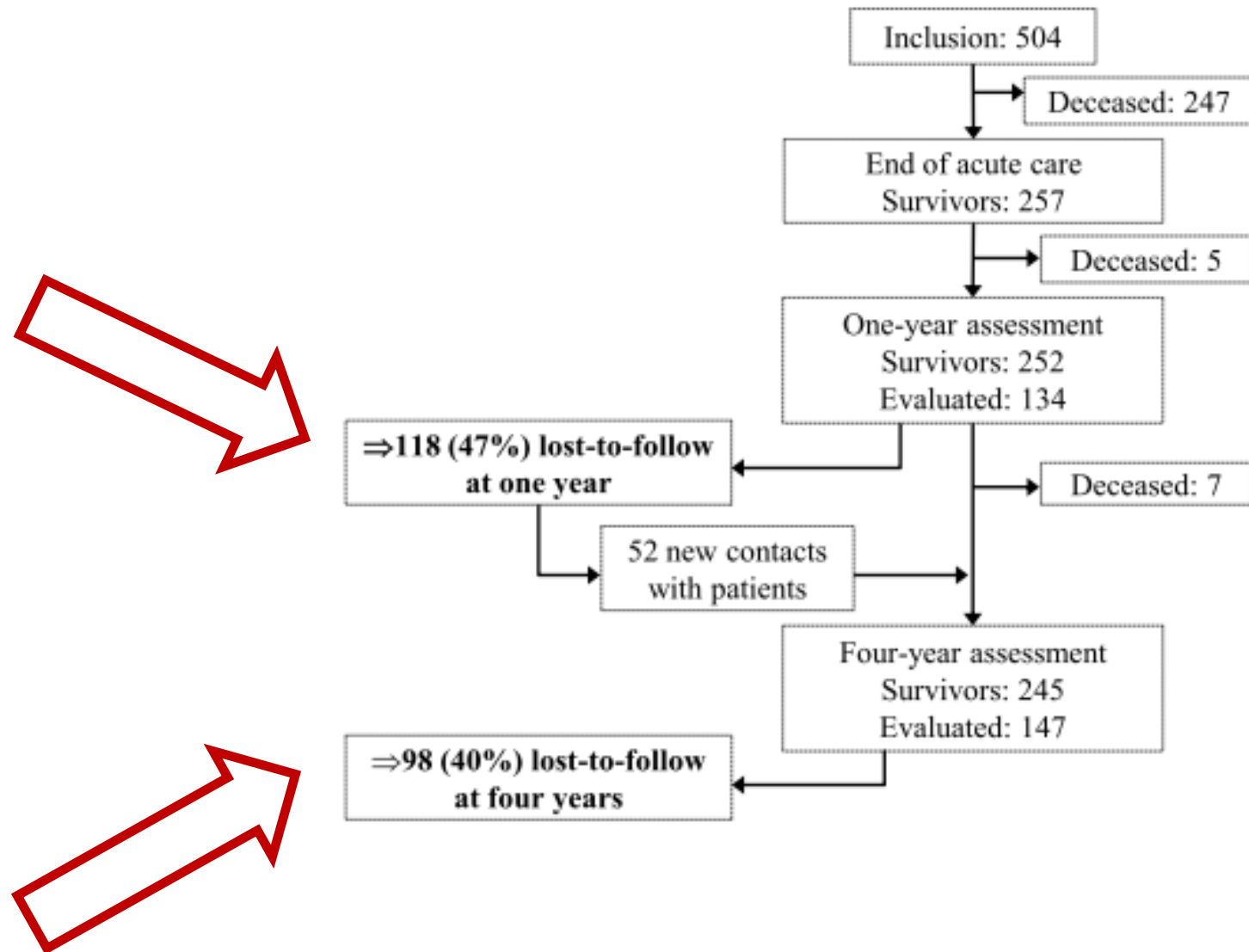
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Lost to follow-up in cohort study



Difficulty for medical follow-up in clinical practice



→ Which patient are most at risk of being lost-to-follow-up ??

At one year

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Variable		p-value (univariate)	p-value (multivariable)
Gender		0.3	
Age		0.2	
Living alone		0.06	
Pre-injury occupation	Working		Ref
	Not working	< 0.05	< 0.05
	Student		0.1
	Retired		0.8
Alcohol history		0.9	
Trauma mechanism	RTA	< 0.01	Ref
	Accidental fall		0.9
	Non accidental fall		< 0.05
	Aggression		< 0.05
Initial GCS		0.2	
Time to follow command		0.6	

Jourdan et al., JHTR, in revision

At four years

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Variable		p-value (univariate)	p-value (multivariable)
Gender		0.6	
Age		0.06	
Living alone		1	
Pre-injury occupation	Working		Ref
	Not working	< 0.05	< 0.01
	Student		0.1
	Retired		0.1
Alcohol history		< 0.05	0.08
Trauma mechanism	RTA	0.6	
	Accidental fall		
	Non accidental fall		
	Aggression		
Initial GCS		0.4	
Time to follow command		0.08	

Jourdan et al., JHTR, in revision

Strengths and weaknesses of PAC in Paris

STRENGTHS

- High rates of rehabilitation services
- Services seem to be provided according to needs
 - Severity
 - Impairments
- Low influence of geographical factors

WEAKNESSES

- Recommended pathways not systematically applied
- Influence of social factors on some services (IR, follow-up)
- Cognitive impairment insufficiently addressed
- Medical and rehab services > > Re-entry services

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Are care pathways related to outcome ?

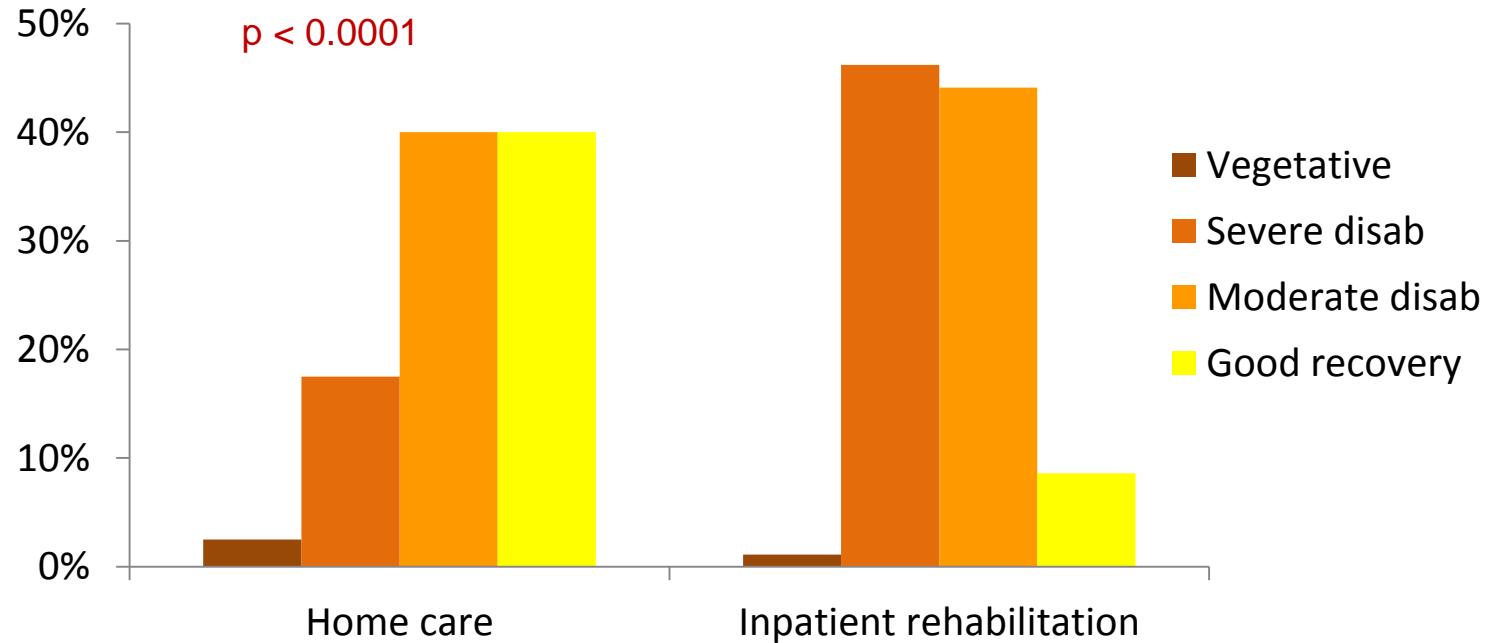
PariS-TBI: worse outcome after inpatient rehabilitation?

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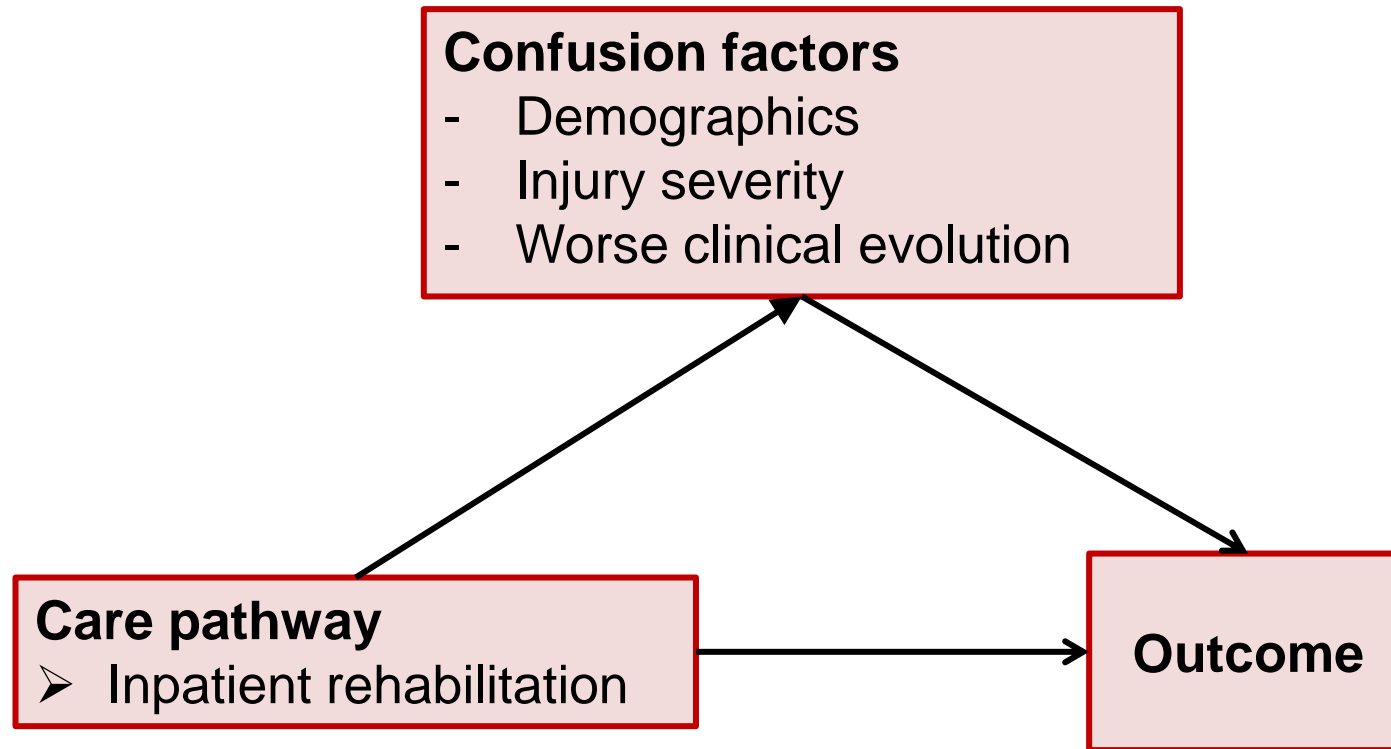
Comparing different systems of care



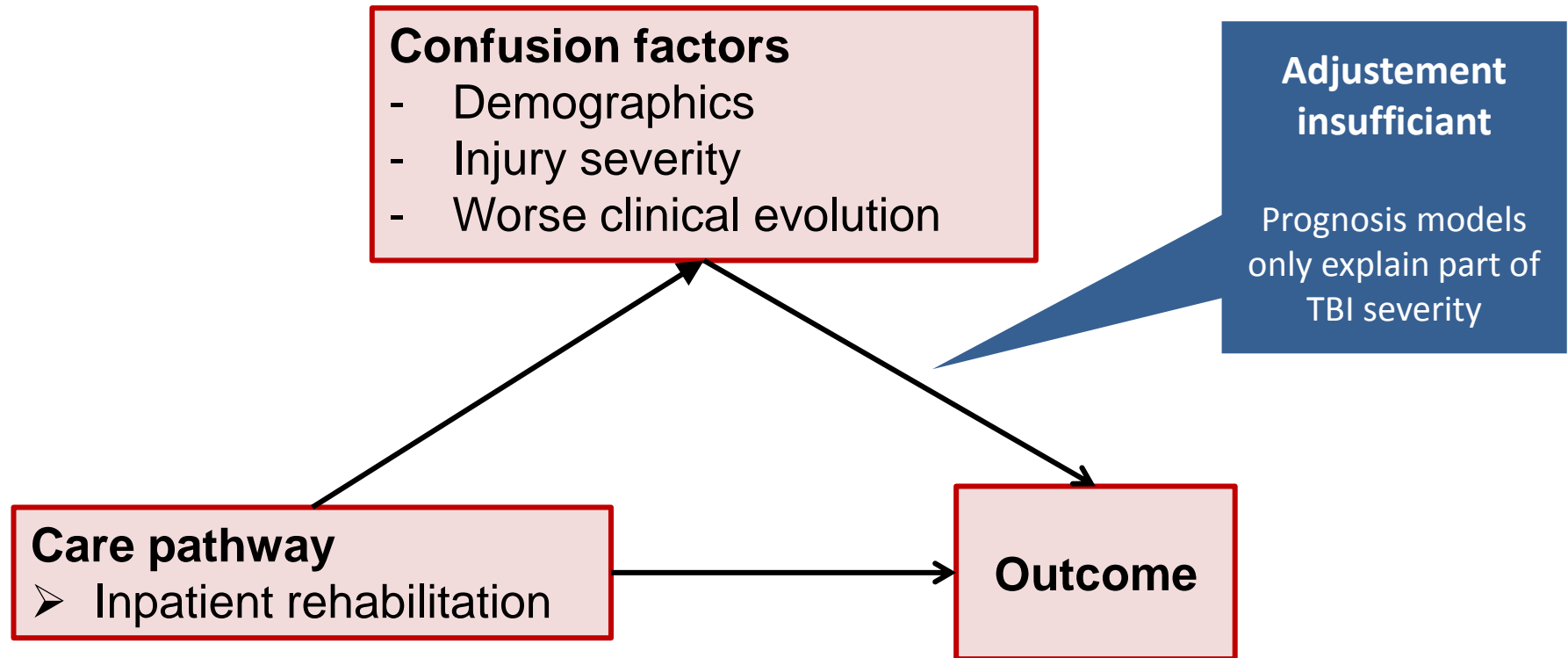
■ Same phenomena in literature

- *Mellick et al., Brain injury 2003*
- *Shafi et al., J Trauma 2007*

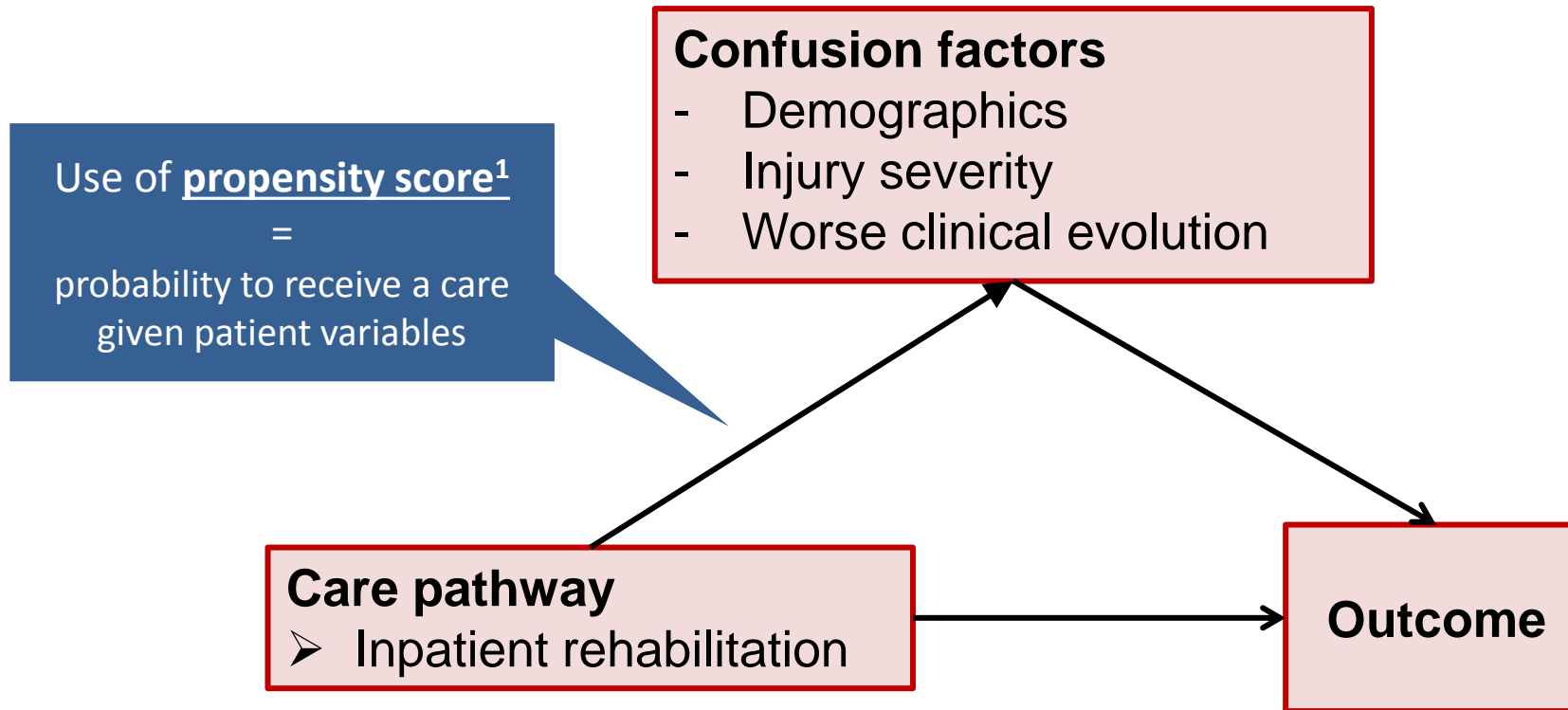
Worse outcome after inpatient rehabilitation?



Worse outcome after inpatient rehabilitation?



Worse outcome after inpatient rehabilitation?



1. Rosenbaum. *The central role of propensity score in observational studies for causal effects.* Biometrika 1983.

Inpatient rehabilitation and outcome – propensity score

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Relation IR and 1-year outcome		p
Odds ratio [IC 95%]		
Favorable outcome		
Univariate analysis	0.28 [0.12 - 0.67]	0.004
Propensity score	0.67 [0.18 - 2.51]	0.5
Return to work		
Univariate analysis	0.55 [0.29 - 1.04]	0.06
Propensity score	0.60 [0.27 - 1.4]	0.2

➔ Insufficient given the magnitude of the difference in population receiving IR or no IR

Using intermediate evaluations

Relating care to patient evolution

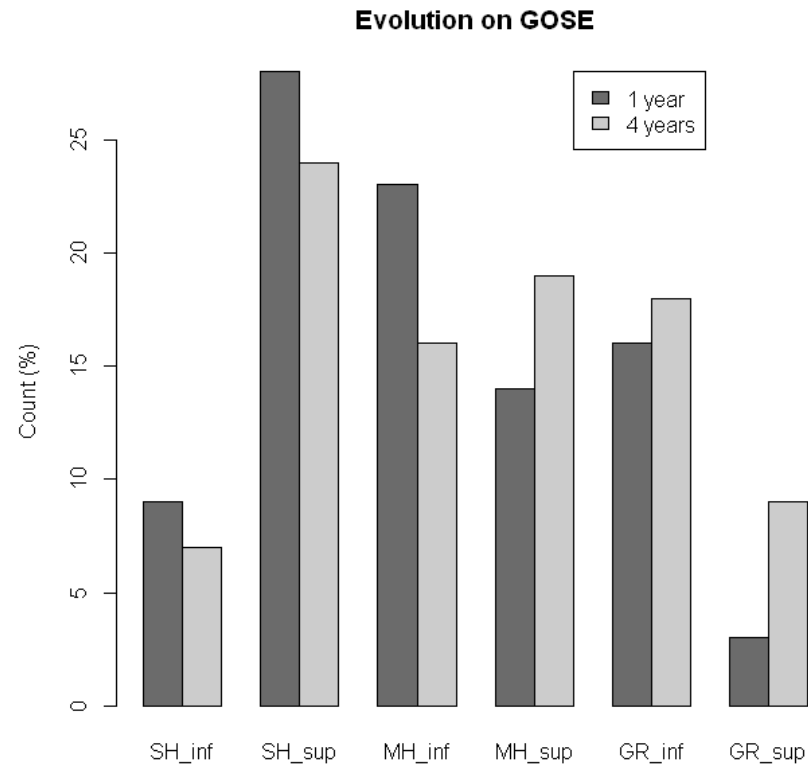
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PariS-TBI: 1-to-4-year evolution (n = 93)



Using intermediate evaluations

Relating care to patient evolution

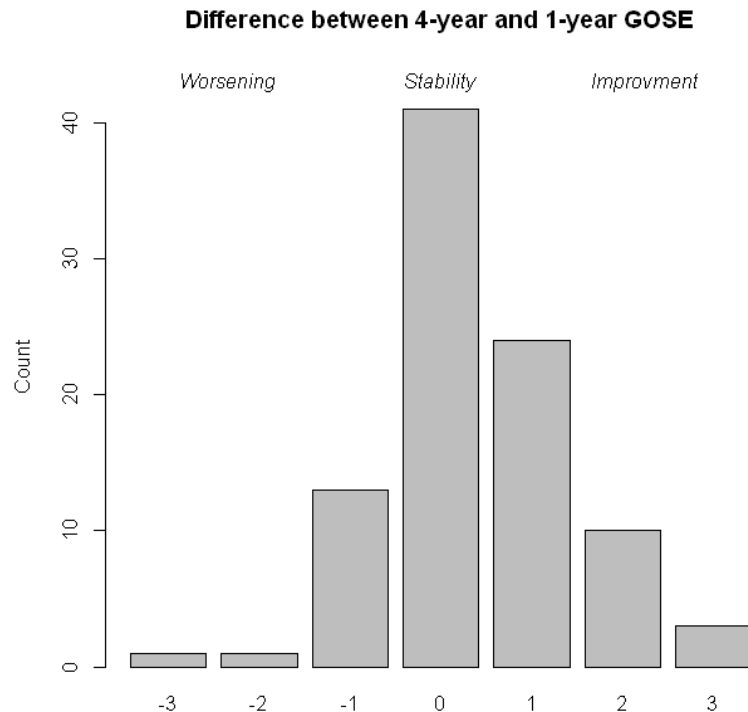
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PariS-TBI: 1-to-4-year evolution (n = 93)



Three groups

- Worsening GOS-E, n = 15
- Stability, n = 41
- Improved GOS-E, n = 37

1-4 year evolution less
dependant on early severity
factors

Using intermediate evaluations

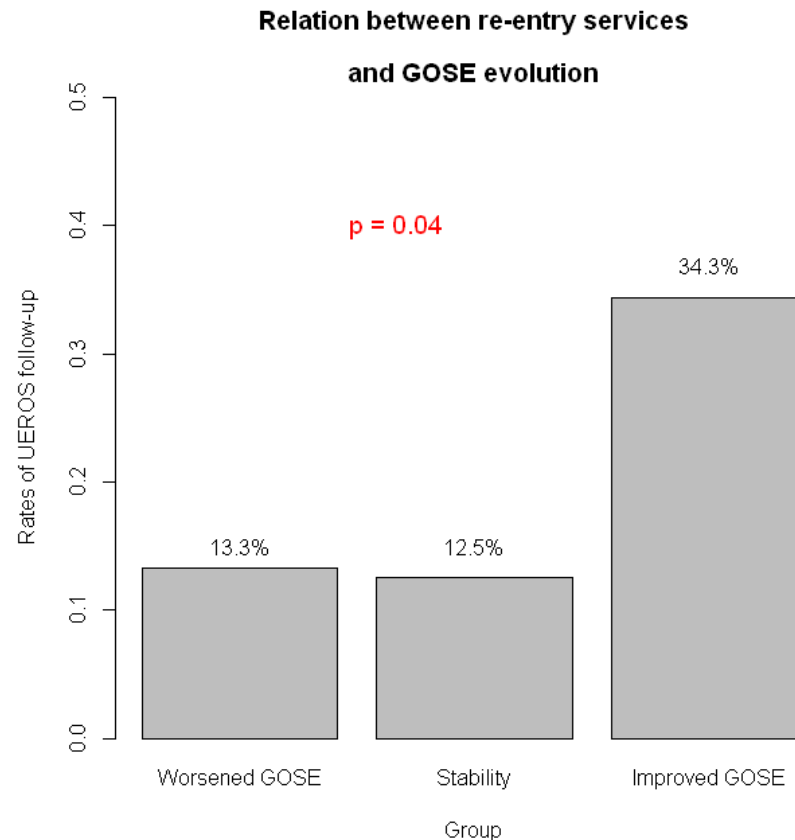
Relating care to patient evolution

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➔ Higher rates of improvements associated with provision of re-entry services

Use of observational data to relate care pathway to outcome

Advantages

- Study of complex interventions, several aspects of care
- Randomization unfeasible

Challenges

- High differences between groups → confusion +++
 - statistical methods insufficient
 - requires higher patient number

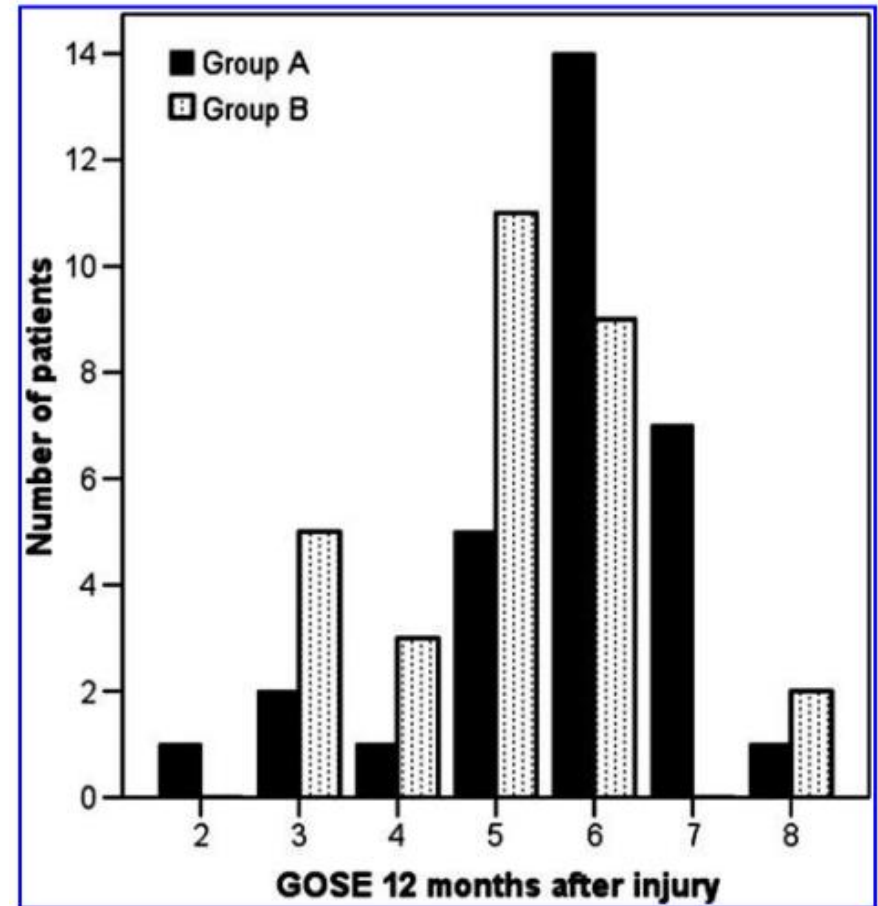
Opportunities

- Study **patient evolution** instead of outcome
- Exploiting situations when differences in care happen « at random »
 - **quasi-experimental design**

Early + continuous care vs discontinuous

Andelic et al., J Neurotrauma, 2012

- Prospective observation cohort
- 61 survivors from severe TBI
 - A = 31 patients « early continuous care »
 - B = 30 patients « discontinuous »
- **Place of care « random »**
(depended on bed availability)
- 1-year functional outcome



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Comparing systems of care



The Paris - Turku project



PariS-TBI study

France

- Cohort of severe TBI patients
- Information on
 - Care pathways; care utilization
 - Determinants of care

Turku University Hospital, TYKS

SouthWest Finland

- Centralized TBI care from ICU to late follow-up
- Experience in international TBI cohorts (TBIcare study)

OBJECTIVES

- Describing care pathways in a similar way in Paris & Turku
- Comparing the two systems → strengths and weaknesses of both?

Preliminary study: Subjective views of professionals

We needed to understand
the **organization of TBI care** and **its issues**
in both systems (Paris and Turku)
before performing any quantitative analysis

➔ Qualitative semi-structured interviews

- Practitioners involved in TBI care
- Different stages: neurosurgeons, ICU practitioners, neurologists, PMR physicians

Questions to health practitioners

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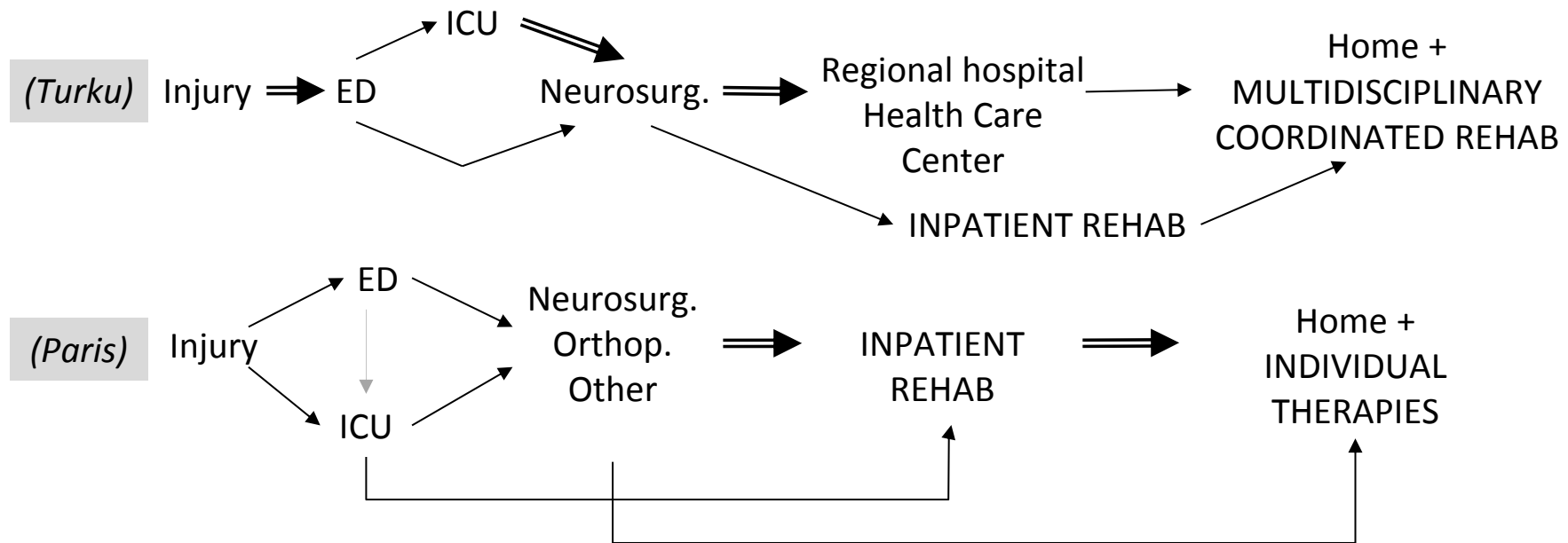
Understanding what happens

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- Organization of TBI care? How is it financed?
- Main places of discharge after each stage of care?
- Usual criteria for place of discharge and who is responsible for the decision?
- What are the issues or problems?

TBI care pathways



Differences in care organization:

- Inpatient vs outpatient rehabilitation +++
- Centralized care versus multiplicity of pathway options ++
- Decision makers and decision criteria for each transition
- Financing of post-acute care

Main problems: **STRUCTURES** of care¹

Issues	Cited in TURKU	Cited in PARIS
Lack of alternatives to inpatient rehabilitation	No day hosp	No coordinated home rehab
Insufficient practitioners for outpatient rehabilitation	Little NP, ST	No OT, NP
Geographical variability in outpatient care	+++	
Lack or re-entry services	Lack of volunteer/leisure activities	Insufficient day programs
Financing of outpatient care	Depends on insurance	No outpatient OT, NP
Heterogeneity of expertise in care	++	++
Complexities owing to multiplicity of places of care		+++

1. Donabedian A. The quality of care. How can it be assessed? JAMA 1988

Main problems: **PROCESSES** of care¹

Issues	Cited in TURKU	Cited in PARIS
Under-diagnosis of TBI	Later difficulties in financing	++
Need for trans-disciplinary decision-making		++
Priority of motor over cognitive training	In acute and post-acute care	All pathway
Delays before beginning of rehabilitation	Need for return home + neurol consult	Waiting for inpatient rehab admission
Lack of objective decision criteria for IR	+	+++
Difficulties with some specific situations	Tracheostomia, disorders of consciousness	Social bakcground, high severity, extra-cranial injuries
Inadequate follow-up of milder TBI patients	-	+++

1. Donabedian A. The quality of care. How can it be assessed? JAMA 1988

Implications...

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Relating care pathway to outcome

Comparing different systems of care

Many issues are similar...

... while local organization of pathways differ...

... and no organization strategy is proven more effective

➔ How is it possible to compare care pathways?

➔ How is it possible to generalize one's findings?

➔ How can we relate cares to outcome?

⇒ **How can we study TBI care pathway in a manner which makes sense for everyone?**

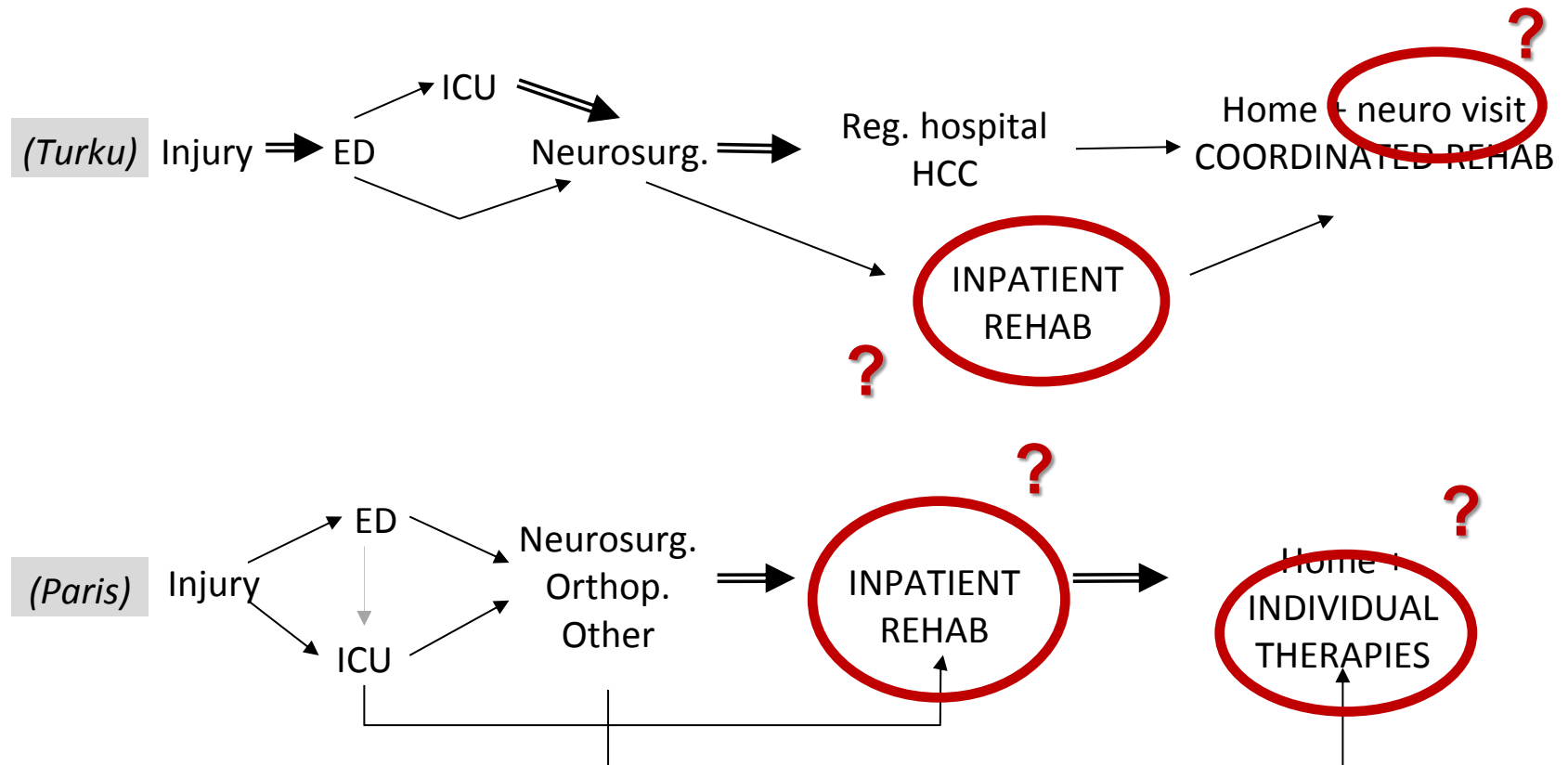
First answer: spot the local critical questions

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➔ ... and compare results:

- ➔ Determinants of pathways → need? social factors?
- ➔ Strengths and weaknesses

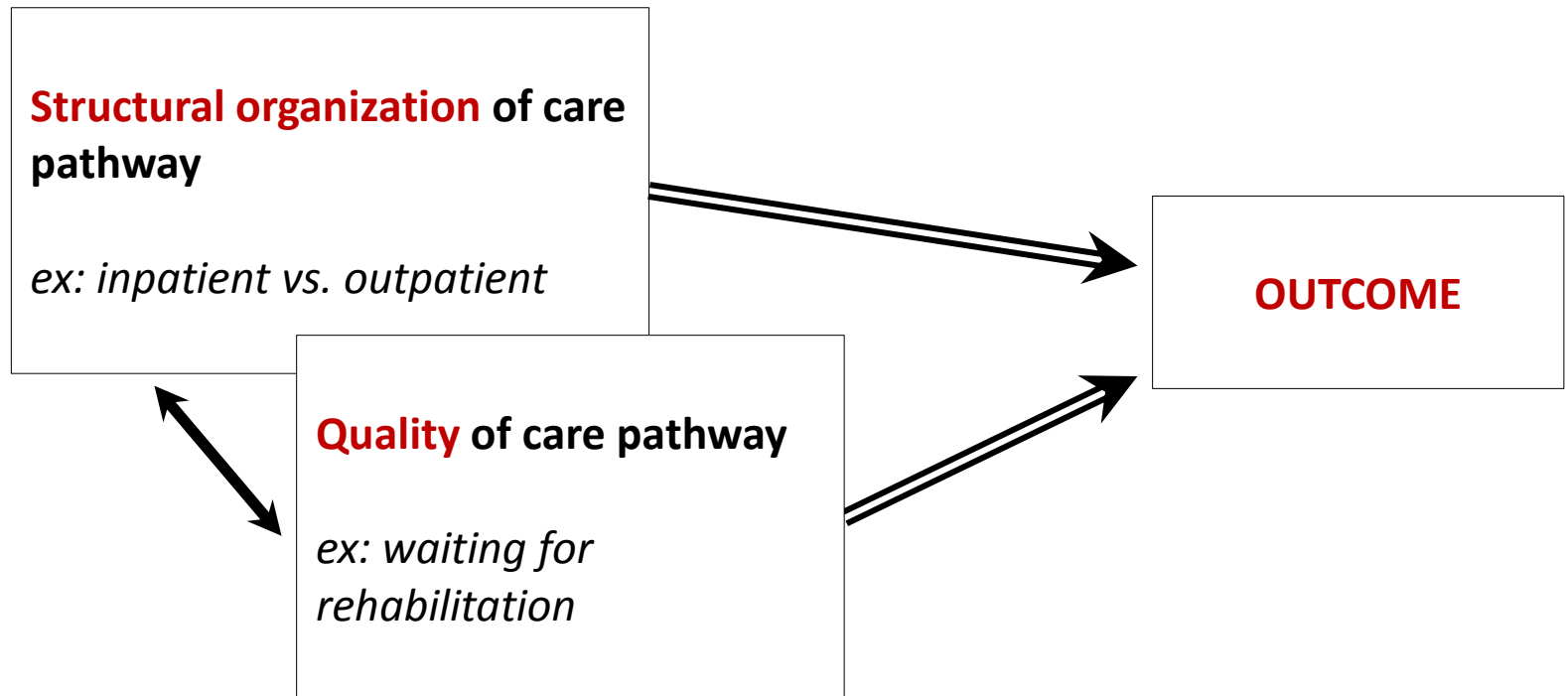
Second answer: care pathway and outcome : Common Model

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To relate care pathway to outcome in multiple care systems, multivariate models need to study impact of **quality aspects** of care **independantly of structure of care pathway**

TBI care pathway and outcome

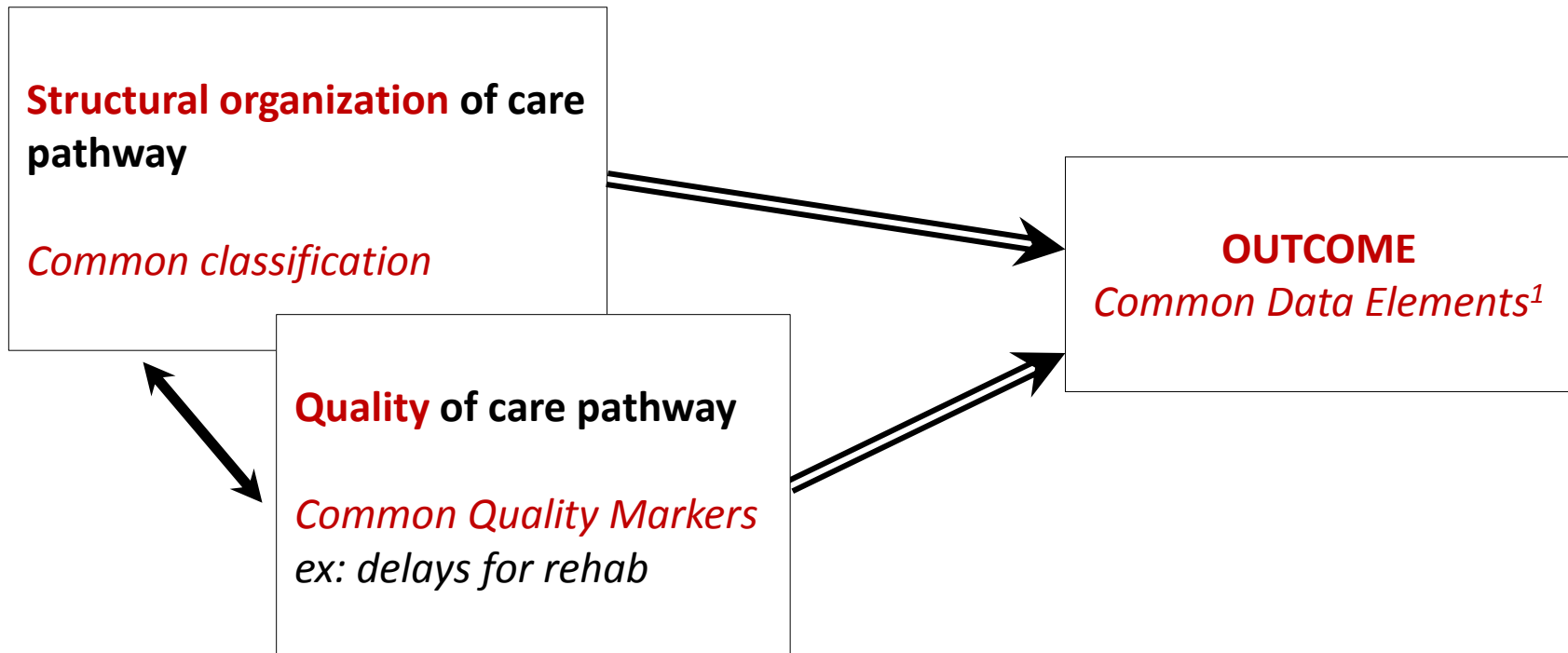
Common Measures

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Common measures need to be used to evaluate

- aspects related to structural organization of care pathways
- aspects related to care quality

1. Whyte. Common data elements. Arch Phys Med Rehab 2010

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happens



Relating care
pathway to outcome

Comparing different
systems of care

Collaborative European NeuroTrauma Effectiveness Research in TBI



CENTER-TBI

The CenterTBI study

Introduction

Understanding what happens

Relating care pathway to outcome

Comparing different systems of care

- Large European project that aims to improve the care for patients with TBI
 - Prospective longitudinal observational study
 - 80 centers; 21 countries; inclusion (start Jan 2015) of 5400 patients
- ➔ Identification of effective medical care, using a comparative effectiveness research approach

<https://www.center-tbi.eu/>

The CenterTBI study

Workpackage 14

Introduction

Understanding what happens

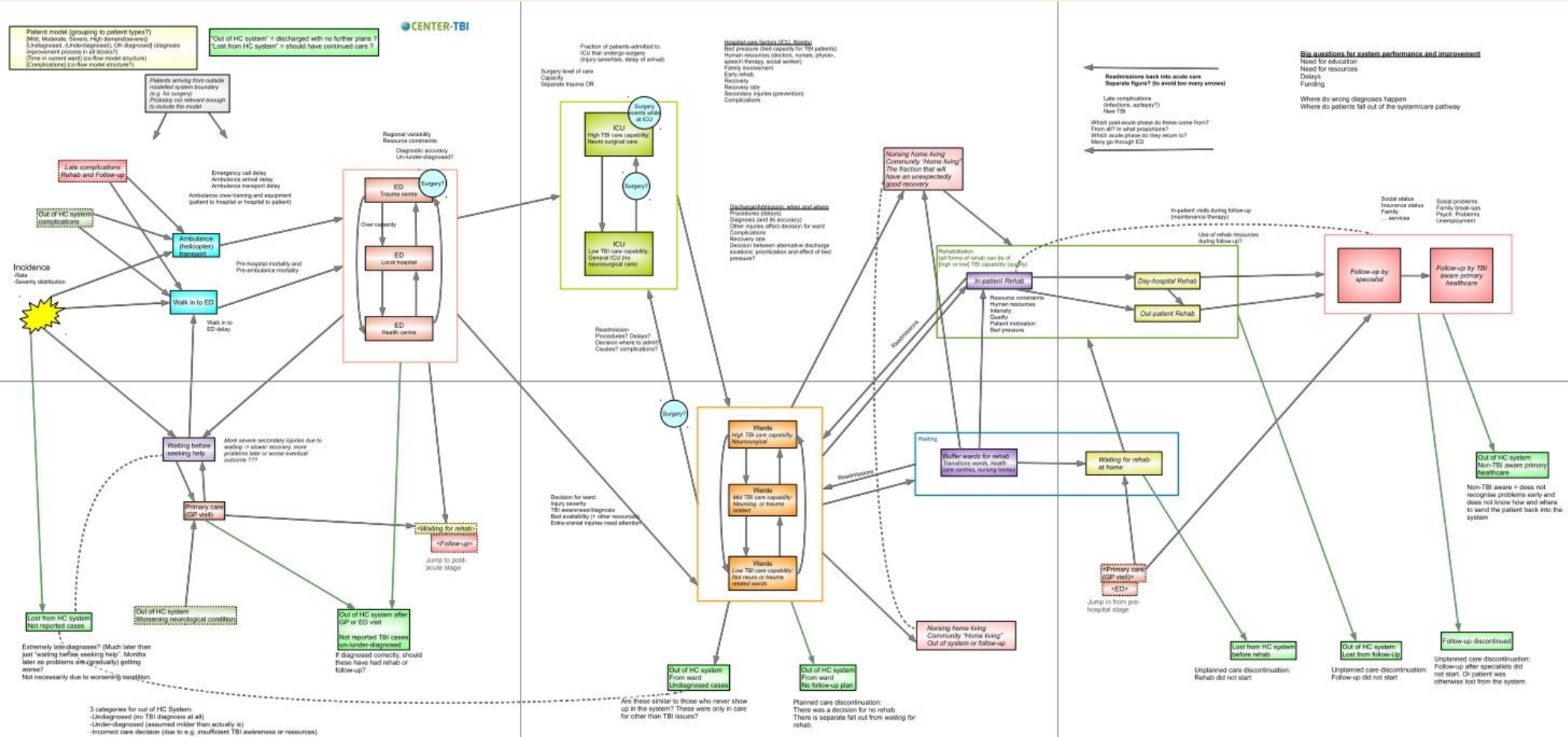
Relating care pathway to outcome

Comparing different systems of care

- “Transitions of care and post-acute care”
 - Team Leader: Pr. Olli Tenovuo, Turku, Finland
 - Partners:
 - Turku University Hospital & VTT Research Centre (Finland)
 - Université Versailles-Saint-Quentin (France)
 - Oslo University Hospital (Norway)
 - Oxford Brookes University (United Kingdom)
 - Trnava University (Slovakia)
- ➔ The study of relation between post-acute care pathway and outcome will be performed on a much larger scale

The CenterTBI study

Dynamic System Modelling



Thank you for your attention

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