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

Claire Jourdan, Physical Medicine and Rehabilitation
University Versailles-Saint-Quentin, France
Introduction
- 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

Relating care pathway to outcome

Comparing different systems of care
- The Paris-Turku project
- The Center-TBI study
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Why severe Traumatic Brain Injuries (TBI)?

- **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

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1. CENTER-TBI study. https://www.center-tbi.eu/
Post-acute care - definitions

- Inpatient Rehabilitation (IR) \( (= \text{hospitalized patient}) \) vs Outpatient Rehabilitation (OR) \( (= \text{day hospital, ambulatory, home-based care}) \)

- 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 care\(^1\)
  - Includes IR, nursing homes, OR, home services...

(Other definition\(^2\)

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

Post-acute care pathways in TBI

Introduction

Understanding what happens

Relating care pathway to outcome

Comparing different systems of care

Katz et al., Brain Injury Medicine. Demos Medical Publishing 2013
Post-acute care pathways in TBI

**Introduction**
- Understanding what happens
- Relating care pathway to outcome
- Comparing different systems of care

**Acute phase**
- Injury
  - Emergency services
  - Acute hospital care
  - Acute inpatient rehabilitation
  - Skilled nursing facility & subacute rehabilitation
  - Residential rehabilitation
  - Home

**Outpatient rehabilitation**
- Individual therapy:
  - Day program
  - Home program

**Community-based services**
- Supported living
- Supported networks
- Support groups
- Recreation groups

**Vocational services**

*Katz et al., Brain Injury Medicine. Demos Medical Publishing 2013*
Post-acute care pathways in TBI

**Introduction**

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Comparing different systems of care

**Sub / post acute phase → rehabilitation**

- **Emergency services** → **Acute hospital care** → **Acute inpatient rehabilitation** → **Skilled nursing facility & subacute rehabilitation** → **Residential rehabilitation** → **Home**

- **Outpatient rehabilitation**: Individual therapy, Day program, Home program

- **Vocational services**: Community-based services: Supported living, Supported networks, Support groups, Recreation groups

*Katz et al., Brain Injury Medicine. Demos Medical Publishing 2013*
Post-acute care pathways in TBI

Introduction: Understanding what happens

Relating care pathway to outcome

Comparing different systems of care

Katz et al., Brain Injury Medicine. Demos Medical Publishing 2013
Evidence for rehabilitation in TBI

RCT or observational studies

- 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
French recommandations (2004) → access to IR for all patients with severe TBI

In 2011 - 2012: « PMR care pathways »

- 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

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

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?
Understanding what happens

Introduction

Understanding what happens

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Comparing different systems of care
The Severe Traumatic Brain Injury in Paris study (PariS-TBI)
The PariS-TBI study

- 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

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

Claire Jourdan, MD,1,2,3 Eleonore Bayen, MD,3,4, Vanessa Bosserelle, MA,5,6 Sylvie Azerad, PharmD,5,6, François Genet, MD,1, Christophe Fermanian, MS,6 Philippe Aegerter, MD, PhD,2,6, Pascale Pradat-Diehl, MD, PhD,3,4, Jean-Jacques Weiss, MD,5, and Philippe Azouvi, MD, PhD,1,2,3, and the Members of the Steering Committee of the PariS-TBI Study

Introduction
Understanding what happens
Relating care pathway to outcome
Comparing different systems of care
## Logistic model: rehabilitation vs. home discharge (n=149)

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

*Jourdan et al., NNR 2013*
Decision of referral to IR and clinical state at the end of ICU

Glasgow Outcome Scale after intensive care and place of post-acute care discharge

IR seems to be related to need

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

Jourdan et al., NNR 2013
**Logistic model: specialised vs. non-specialised rehabilitation (n=136)**

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

* Jourdan et al., NNR 2013
Other results – acute and post-acute pathways

- **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
PariS-TBI: utilization of health care resources up to 4 years post-injury
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Relating care pathway to outcome

Comparing different systems of care

Jourdan et al., Brain Injury, in revision
High rates of medical services
... but 63% specialist follow-up only

Jourdan et al., Brain Injury, in revision
High rates of rehabilitation services
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 \(\rightarrow\) physiotherapy
    - Pain \(\rightarrow\) physiotherapy \(\rightarrow\) speech therapy
    - Anxiety and depression \(\rightarrow\) psychotherapy
    - Speech & language impairments \(\rightarrow\) speech therapy

*Jourdan et al., Brain Injury, in revision*
Which factors influence health care utilization (HCU)?

1. Needs

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

Jourdan et al., Brain Injury, in revision
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)

Jourdan et al., Brain Injury, in revision
Specific patient profile for re-entry services

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

Rate of UEROS and GOSE

Jourdan et al., Brain Injury, in revision
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PariS-TBI: lost to follow-up
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

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

*Jourdan et al., JHTR, in revision*
At four years

<table>
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<th>Variable</th>
<th>p-value (univariate)</th>
<th>p-value (multivariable)</th>
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<tr>
<td>Gender</td>
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<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.06</td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Pre-injury occupation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>Ref</td>
<td></td>
</tr>
<tr>
<td>Not working</td>
<td>&lt; 0.05</td>
<td>&lt; 0.01</td>
</tr>
<tr>
<td>Student</td>
<td></td>
<td>0.1</td>
</tr>
<tr>
<td>Retired</td>
<td></td>
<td>0.1</td>
</tr>
<tr>
<td>Alcohol history</td>
<td>&lt; 0.05</td>
<td>0.08</td>
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<tr>
<td>Trauma mechanism</td>
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</tr>
<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Aggression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial GCS</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td>Time to follow command</td>
<td></td>
<td>0.08</td>
</tr>
</tbody>
</table>

*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
Are care pathways related to outcome?
PariS-TBI: worse outcome after inpatient rehabilitation?

- Same phenomena in literature
  - Mellick et al., Brain injury 2003
  - Shafi et al., J Trauma 2007
Worse outcome after inpatient rehabilitation?

Confusion factors
- Demographics
- Injury severity
- Worse clinical evolution

Care pathway
- Inpatient rehabilitation

Outcome
Worse outcome after inpatient rehabilitation?

Confusion factors:
- Demographics
- Injury severity
- Worse clinical evolution

Care pathway:
- Inpatient rehabilitation

Outcome

Adjustement insufficient
Prognosis models only explain part of TBI severity
Worse outcome after inpatient rehabilitation?

Confusion factors
- Demographics
- Injury severity
- Worse clinical evolution

Care pathway
- Inpatient rehabilitation

Outcome

Use of propensity score
= probability to receive a care given patient variables

## Inpatient rehabilitation and outcome – propensity score

<table>
<thead>
<tr>
<th></th>
<th>Favorable outcome</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relation IR and 1-year outcome</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Odds ratio [IC 95%]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Univariate analysis</td>
<td>0.28 [0.12 - 0.67]</td>
<td>0.004</td>
</tr>
<tr>
<td>Propensity score</td>
<td>0.67 [0.18 - 2.51]</td>
<td>0.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Return to work</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Univariate analysis</strong></td>
<td>0.55 [0.29 - 1.04]</td>
<td>0.06</td>
</tr>
<tr>
<td><strong>Propensity score</strong></td>
<td>0.60 [0.27 - 1.4]</td>
<td>0.2</td>
</tr>
</tbody>
</table>

➔ Insufficient given the magnitude of the difference in population receiving IR or no IR
Using intermediate evaluations
Relating care to patient evolution

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

Evolution on GOSE

<table>
<thead>
<tr>
<th>Condition</th>
<th>1 year</th>
<th>4 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>SH_inf</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SH_sup</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MH_inf</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MH_sup</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GR_inf</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GR_sup</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Using intermediate evaluations
Relating care to patient evolution

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

Three groups
- Worsening GOSE, n = 15
- Stability, n = 41
- Improved GOSE, n = 37

1-4 year evolution less dependant on early severity factors
Using intermediate evaluations
Relating care to patient evolution

Introduction
Understanding what happens
Relating care pathway to outcome
Comparing different systems of care

Relation between re-entry services and GOSE evolution

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

\[ p = 0.04 \]
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 care
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

![Bar chart showing GOSE 12 months after injury for Group A and Group B.](chart.png)
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 preforming any quantitative analysis.

Qualitative semi-structured interviews

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

- 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?
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 care**

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

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1. Donabedian A. The quality of care. How can it be assessed? JAMA 1988
Main problems: **PROCESSES of care**

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

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

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

... and compare results:
- Determinants of pathways → need? social factors?
- Strengths and weaknesses
Second answer: care pathway and outcome: Common Model

To relate care pathway to outcome in multiple care systems, multivariate models need to study impact of quality aspects of care independently of structure of care pathway.
Common measures need to be used to evaluate
- aspects related to structural organization of care pathways
- aspects related to care quality

Collaborative European NeuroTrauma Effectiveness Research in TBI
The CenterTBI study

- 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

- “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)
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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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