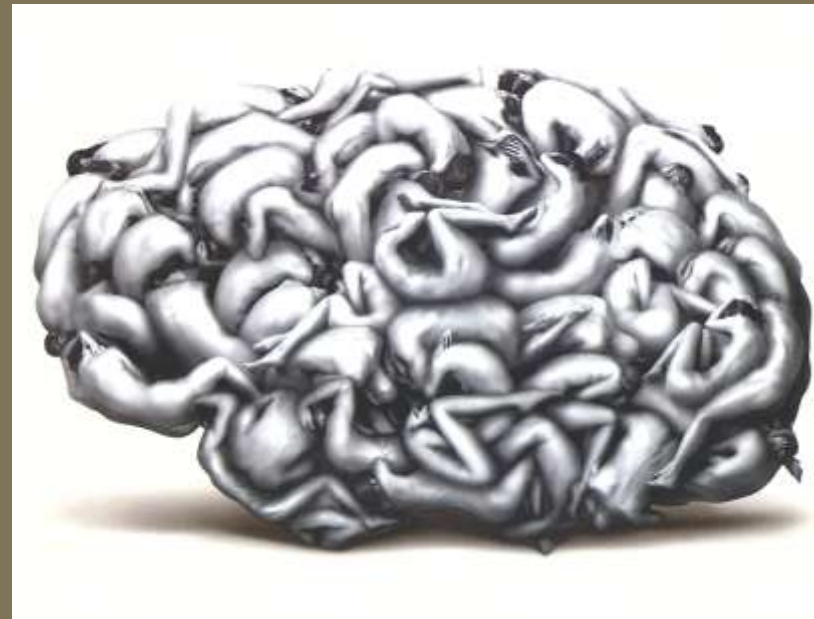


# DEVELOPMENT OF A STANDARDIZED REGISTRATION AND FOLLOW-UP SYSTEM FOR DOC PATIENTS Belgian Federal Project

**Marie-Aurélié Bruno**  
**Neuropsychologist**  
**PhD in Medical Sciences**

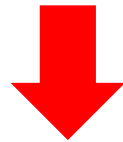
**Coma Science Group**  
**Cyclotron Research Centre**  
**CHU Sart-Tilman**  
**Liège, Belgium**



[www.comascience.org](http://www.comascience.org)

# Background

- **2001**: Working group on acquired brain injury
- **2004**: Pilot Project – Network of care for DOC patients
- **2007**: Clinical practice guidelines for DOC patients

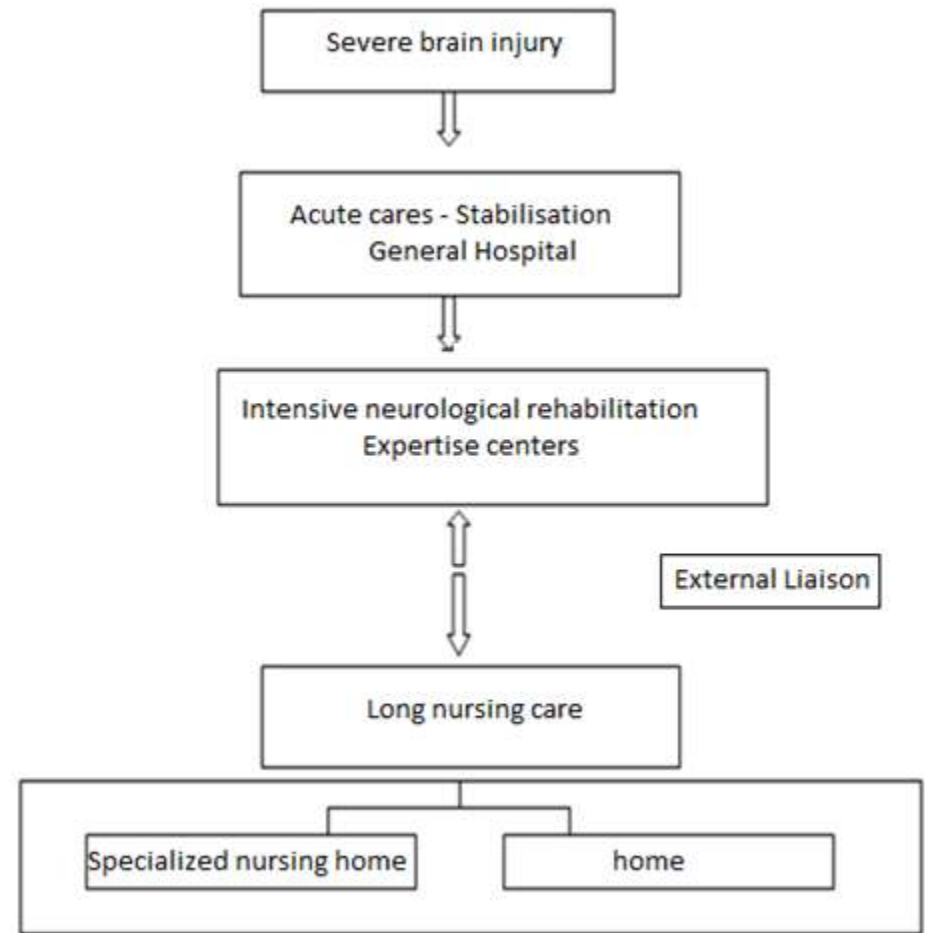


**Harmonize the chronic cares and the rehabilitation needs**

# Background

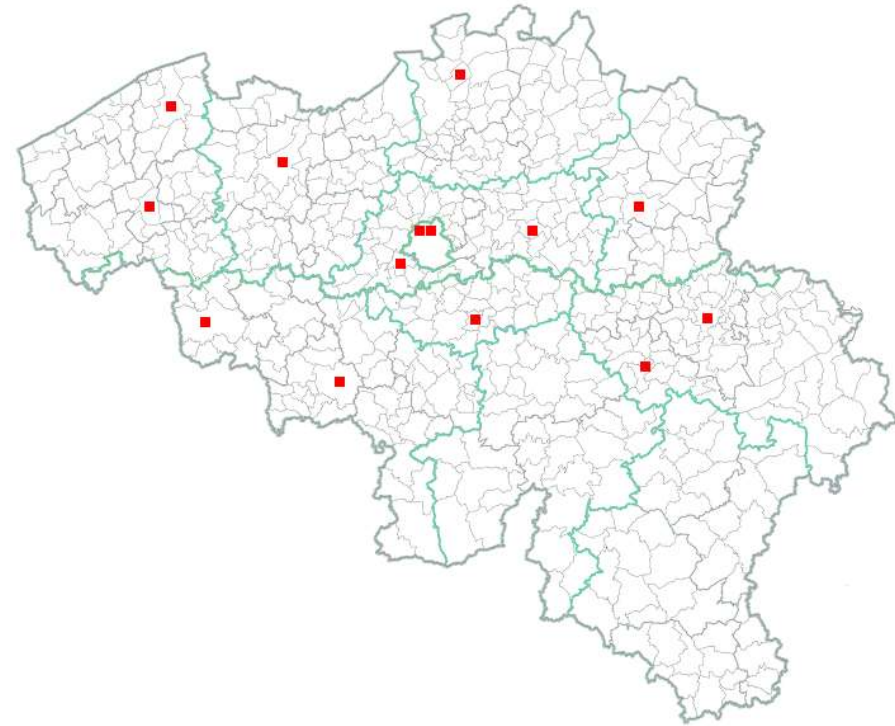
## Health care circuit:

- Collect quantitative/qualitative epidemiologic, clinical, medical data
- Provide information about available vacancies
- Avoid to leave the circuit
- Optimize the patient flux



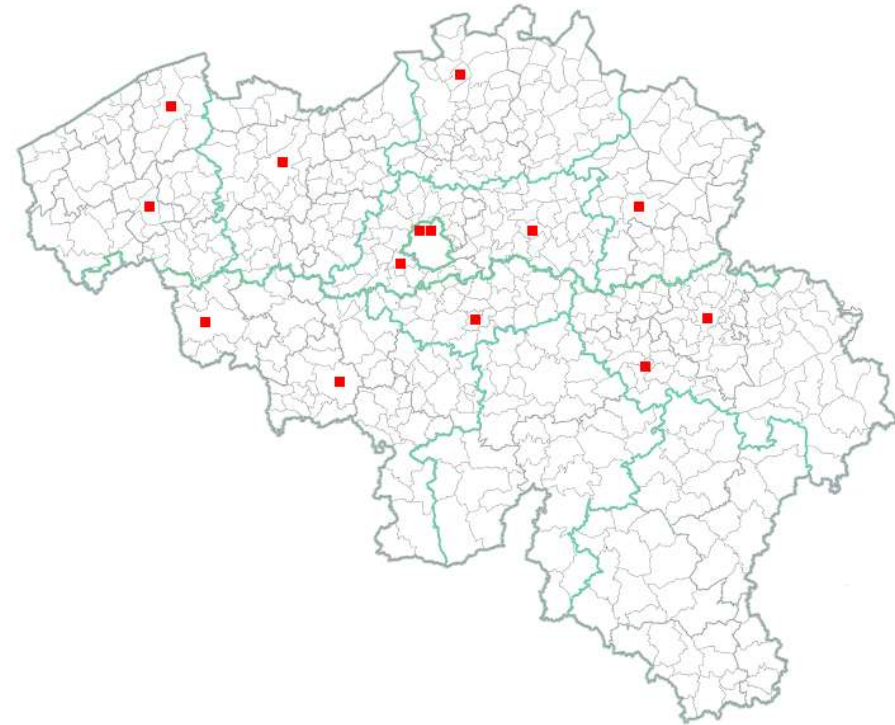
# Belgian Federal Network

16 expertise centers  
(80 beds)



# Belgian Federal Network

16 expertise centers  
(80 beds)

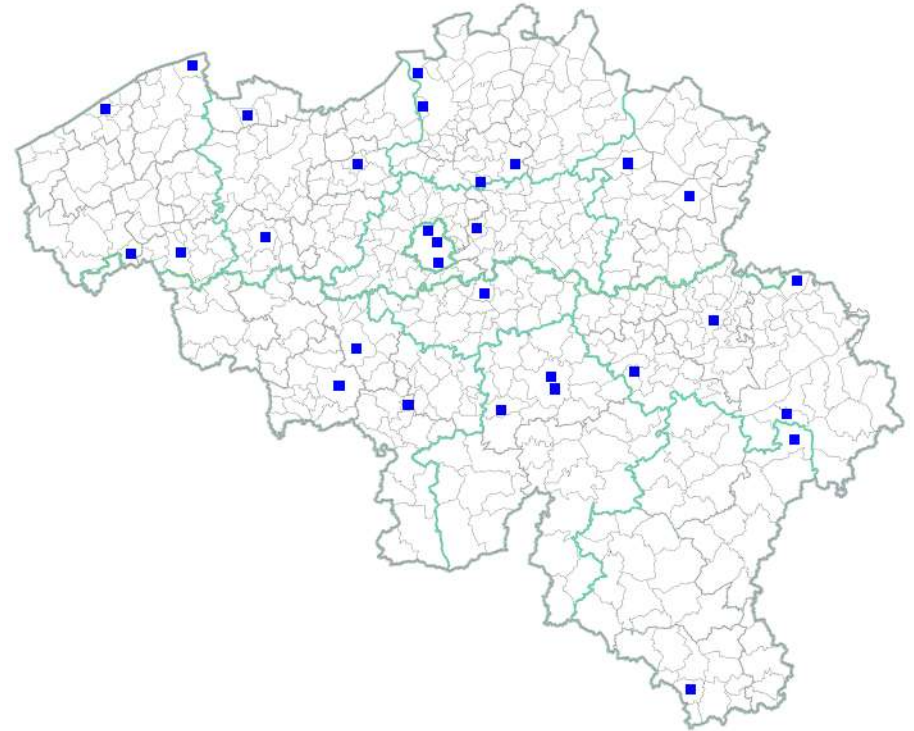
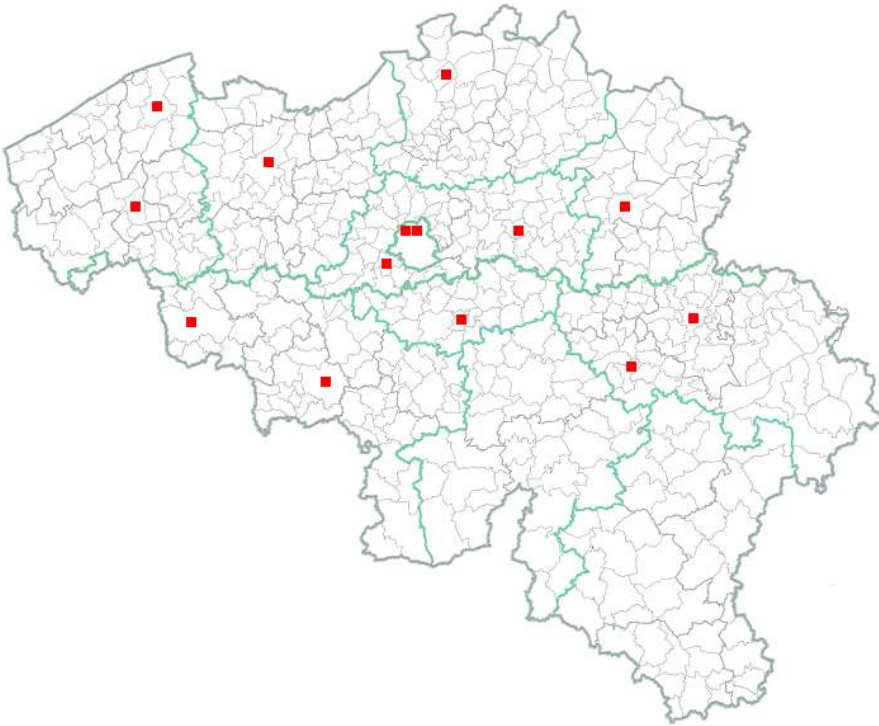


- $\geq 5$  beds
- Physicians/nurses monitoring
- Multidisciplinary team
- Functional rehabilitation department
- Hospital referent(s) – external liaison
- Adapted equipment
  - x Suction bronchial device
  - x Pulse oximeter
  - x Mattresses against pressure ulcers
  - x Rehabilitation equipment
  - x Lift-system
  - x Adapted bathtub/bed
  - x Wheelchair

# Belgian Federal Network

16 expertise centers  
(80 beds)

30 accredited convalescent  
home (165 beds)



# Coma Recovery Scale-Revised

**CRS-R**  
**COMA RECOVERY SCALE-REVISED**

ÉCHELLE DE RÉCUPÉRATION DU COMA  
 VERSION REVUE FRANÇAISE 2004

Livret d'évaluation et d'administration

Joseph T. Giacino, Ph.D. et Kathleen Kalmar, Ph.D.  
 Center for Head Injuries  
 Edison, New Jersey

**JFK**  
 Johnson Rehabilitation Institute  
 Affiliated with JFK Medical Center

**SOLARIS**  
 MEDICAL CENTER

Adaptation française - Version 29 octobre 2004

Steven Laureys  
 Coma Science Group, Université de Liège  
 www.comascience.org

SPF Santé Publique  
 www.health.gov.be/coma



**\*SELF-STUDY DVD OFFER\***

**COMA RECOVERY SCALE - REVISED:  
 GUIDELINES FOR ADMINISTRATION AND  
 SCORING**

[coma@chu.ulg.ac.be](mailto:coma@chu.ulg.ac.be)



**JFK COMA RECOVERY SCALE - REVISED** 2004  
 Record Form

Patient: \_\_\_\_\_ Date: \_\_\_\_\_

AUDITORY FUNCTION SCALE	
4 - Consistent Movement to Command *	
3 - Reproducible Movement to Command *	
2 - Localization to Sound	
1 - Auditory Startle	
0 - None	

VISUAL FUNCTION SCALE	
5 - Object Recognition *	
4 - Object Localization: Reaching *	
3 - Visual Pursuit *	
2 - Fixation *	
1 - Visual Startle	
0 - None	

MOTOR FUNCTION SCALE	
0 - Functional Object Use †	
5 - Automatic Motor Response *	
4 - Object Manipulation *	
3 - Localization to Noxious Stimulation *	
2 - Flexion Withdrawal	
1 - Abnormal Posturing	
0 - None/Flaccid	

GROMOTOR/VERBAL FUNCTION SCALE	
3 - Intelligible Verbalization *	
2 - Vocalization/Oral Movement	
1 - Oral Reflexive Movement	
0 - None	

COMMUNICATION SCALE	
2 - Functional: Accurate †	
1 - Non-Functional: Intentional *	
0 - None	

AROUSAL SCALE	
3 - Arousal	
2 - Eye Opening w/o Stimulation	
1 - Eye Opening with Stimulation	
0 - Unarousable	

TOTAL SCORE	



# Case Report Form

BDD\_22022010.xls [Compatibility Mode] - Microsoft Excel

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Protect Sheet Protect Workbook Share Workbook Track Changes Changes

Protect and Share Workbook Allow Users to Edit Ranges

J12 GENK - ZIEKENHUIS OOST - LIMBURG

	A	B	C	D	E	F	G	H	I
1	Centre d'expertise	Numéro interne patient	CODE	Nom	Prénom	Date de naissance	Sexe	Age événement	Code postal
2		01/09786542/1	T1895335				Homme	55	351
3		01/09957531/1	XT2300524				Homme	45	249
4		01/10020121/1	LE2091735				Homme	50	354
5		01/10071637/1	NA2456938				Femme	40	384
6		01/10215341/1	E1812422				Femme	58	223
7		01/10558377/1	TE1088639				Femme	77	397
8		01/10694909/1	XS972038				Homme	81	389
9		01/10836294/1	NO2095524				Homme	51	249
10		01/10955946/1	SM2169222				Homme	49	226



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ABC Spelling Research Thesaurus Translate Proofing

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5		Femme	58	223
6		Femme	77	397
7		Homme	81	389
8		Homme	51	249
9		Homme	49	226

A2

	A	Nu
1	Centre d'expertise	
2		
3	Algemeen Ziekenhuis Sint-Jan, Brugge	
4	Universitair Ziekenhuis Gent	
5	Algemeen Ziekenhuis Salvator – Sint. Ursula, Hasselt	
6	Heropbeuring vzw De Mick, Brasschaat	
7	Universitair Ziekenhuis Leuven, Pellenberg	
8	Ziekenhuis Inkendaal, Wezenbeek	
9	AZ zusters van Barmhartigheid, Ronse	
10	Centre Hospitalier Régional de Tournai, Tournai	

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9		01/10836294/1	NO2095524				Homme	51	249
10		01/10955946/1	SM2169222				Homme	49	226



# Case Report Form

Z	AA	CRS ORC
CRS VISUELLE - admission	CRS MOTRICE - admission	CRS ORC
<input type="text" value="0"/>	<b>FONCTION VISUELLE</b> 5 – Reconnaissance des objets* 4 – Localisation des objets : atteinte* 3 – Poursuite visuelle* 2 – Fixation* 1 – Réflexe de clignement à la menace 0 – Néant	

M	N	O	P	Q	R	S
Statut lors de la sortie	Statut lors de la sortie	Statut lors de la sortie	Statut lors de la sortie	Statut lors de la sortie	Statut lors de la sortie	Statut lors de la sortie
Transfert vers	Date de transfert	Diagnostic donné par le référent	Diagnostic à l'admission	Statut lors de 3 mois	Statut lors de 6 mois	Statut à 1an
MRS agréée	12/11/2007	Coma	Etat végétatif			
autre hôpital - SP/rééducation	22/10/2008	Etat végétatif	Etat de conscience minimale			
décès	12/10/2007	Etat végétatif	Etat végétatif			
décès	11/01/2008	Coma	Coma			
autre hôpital - SP/rééducation	10/06/2008	Coma	Etat végétatif			

# Epidemiologic data – 2009

- 16 expertise centers
- 187 admissions (60% men)
- Age: 52 18y, min 14 – max 91 (3 patients < 18 ans)
- Etiologies: 65% non-traumatic
- Clinical status on admission:
  - 5% coma
  - 34% VS/Unresponsive Wakefulness Syndrome
  - 42% MCS
  - 6% Exit MCS
  - 2% Locked-in syndrome
  - 11% unknow

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# Flux/Cost-benefit analysis

<b>Expertise center</b>	<b>Beds (N)</b>	<b>Admission (N)</b>	<b>Occupancy rate Mean±SD (min, max)</b>	<b>% rate Mean (min, max)</b>
<b>Center 1</b>	19	38	15±3 (8-20)	79% (42%-105%)
<b>Center 2</b>	6	17	6±1 (4-8)	100% (66%-133%)
<b>Center 3</b>	6	9	5±1 (2-8)	83% (33%-133%)
<b>Center 4</b>	6	12	2±1 (0-4)	33% (0%-66%)

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## **Waiting time admission expertise center**

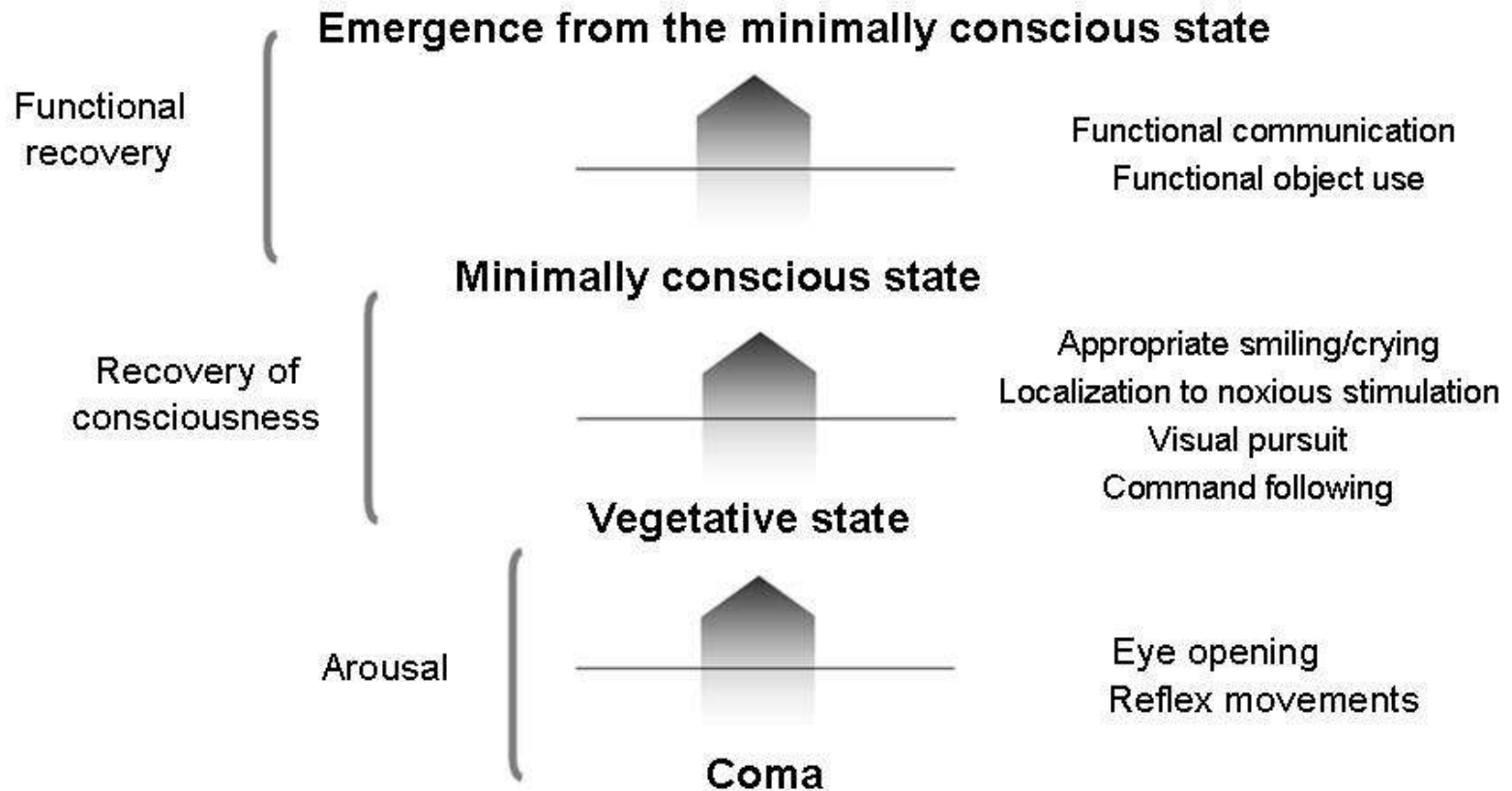
- Mean 26 34 days (median 13; range 0-10 months)
- 26 days \* cost per day in acute care hospital (xxx €) = xxx € / patient

## **Waiting time admission nursing center**

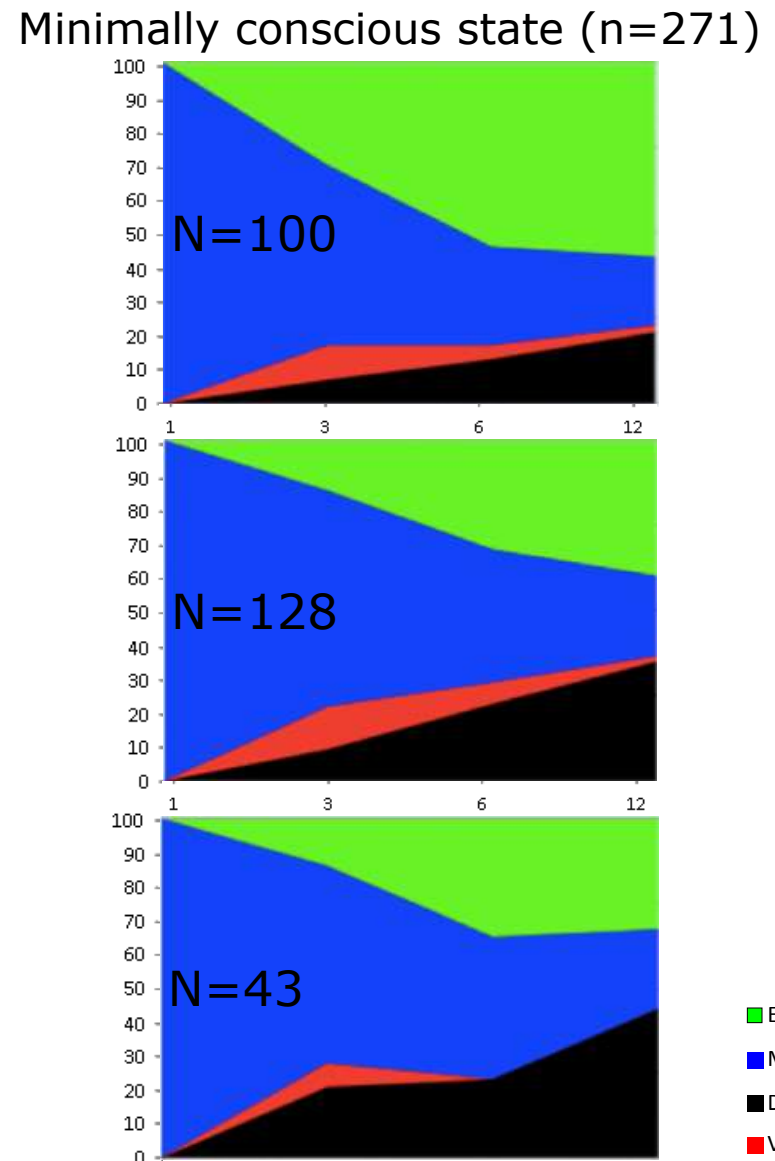
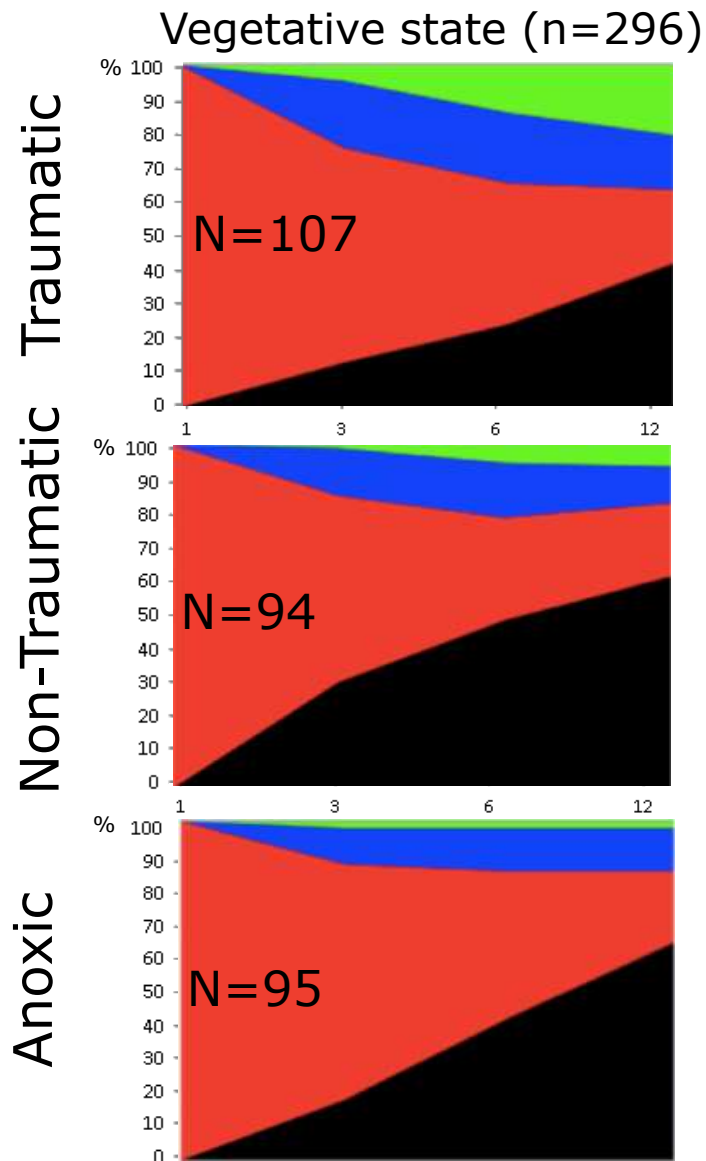
- Mean 67 99 days (median 34; range 0-2 years)
- 67 days \* cost per day in rehab hospital (xxx €) = xxx € / patient



# OUTCOME



# OUTCOME

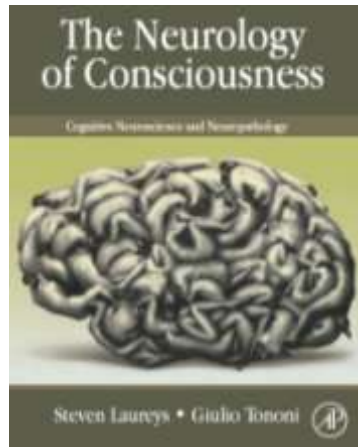


# Conclusions

- **Centralized database** – Expertise center/Nursing home
- **Inclusion criteria** – Exit MCS/Locked-In syndrome/<18y
- **CRS-R at 1, 3, 6, 12 and 24 post-injury**
- **Functional recovery** - Glasgow Outcome-Scale Extended
- **Optimize the patient flux**
- **Admission/discharge criteria** – Expertise center/Nursing home



[coma@chu.ulg.ac.be](mailto:coma@chu.ulg.ac.be)



James S. McDonnell Foundation



[www.comascience.org](http://www.comascience.org)

# CRF\* - Epidemiology

**Unique patient identifiers:** ID number

**Date of birth:** extract this number thanks to the ID number

**Date of the causative incident:** mm/dd/yyyy

**Age at onset:**

**Sex:** male-female

**ZIP code:** before the onset

**Marital status:**

**Professional status:** Worker  
Pupil/student  
Unemployed  
Housewife/husband  
Other  
Unknown

**Level of education:** primary education (primary schools)  
secondary education (secondary schools/high schools)  
tertiary education (university and/or TAFE colleges)

**Nationality:**

**Insurance status:**

**Complementary insurance policy:** yes/no

# CRF – Clinical information (1)

## **Etiology**

### ***Traumatic***

Subdural hematoma  
Epidural hematoma  
Contusion  
Diffuse axonal injury

### ***Non-traumatic***

Subarachnoidal hemorrhage  
Hemorrhagic stroke otherwise  
Ischemic stroke  
Anoxia during circulatory arrest  
Anoxia due to other cause  
Infection of the central nervous system  
Intoxication  
Metabolic disorder  
Combination

**Date of arrival at the expertise center:** mm/dd/yyyy

**Expertise center:** Belgian list

**Vegetative state/unresponsive wakefulness syndrome:** date of eye opening - mm/dd/yyyy - Unknow

**Coma duration:** xx days

**Date of MCS:** clinical criteria (non-reflex movement) - mm/dd/yyyy

**Duration of VS/unresponsive wakefulness syndrome:** xx days

**Date of Exit-MCS:** clinical criteria - mm/dd/yyyy

**Duration of MCS:** xx days

# CRF – Clinical information (2)

**Date of the dead:** mm/dd/yyyy

**Age at the time of the dead:**

**Cause of death:**

- Natural death
- Diseases of the circulatory
  - including ischemic heart disease
  - with cerebrovascular disease
- Tumor
- Respiratory diseases
- Digestive Diseases
- Nervous system diseases
- Infectious and parasitic diseases
- Suicides
- Traffic accidents
- Violent death
- Accidental falls
- Other
- Discontinuation of treatment
- Treatment uninitiated

# CRF – Clinical information (3)

## CRS-R expertise center admission:

### AUDITORY FUNCTION SCALE

- 4 - Consistent Movement to Command
- 3 - Reproducible Movement to Command
- 2 - Localization to Sound
- 1 - Auditory Startle
- 0 - None

### VISUAL FUNCTION SCALE

- 5 - Object Recognition
- 4 - Object Localization: Reaching
- 3 - Visual Pursuit
- 2 - Fixation
- 1 - Visual Startle
- 0 - None

### MOTOR FUNCTION SCALE

- 6 - Functional Object Use
- 5 - Automatic Motor Response
- 4 - Object Manipulation
- 3 - Localization to Noxious Stimulation

### CRS-R 3 months post-injury

### CRS-R 6 months post-injury

### CRS-R 12 months post-injury

### CRS-R at the time of the release from the expertise center

### OROMOTOR/VERBALFUNCTION SCALE

- 3 - Intelligible Verbalization
- 2 - Vocalization/Oral Movement
- 1 - Oral Reflexive Movement
- 0 - None

### COMMUNICATION SCALE

- 2 - Functional: Accurate"
- 1 - Non-Functional: Intentional \*
- 0 - None

### AROUSAL SCALE

- 3 - Attention
- 2 - Eye Opening w/o Stimulation
- 1 - Eye Opening with Stimulation
- 0 - Unarousable

### TOTAL SCORE

### Admission status (linked with the CRS-R score):

- VS/UWS
- MCS
- EXIT-MCS
- LIS

### Status at 3 months post-onset (linked with the CRS-R score):

- VS/UWS
- MCS
- EXIT-MCS
- LIS
- Dead

### Status at 6 months post-onset (linked with the CRS-R score):

- VS/UWS
- MCS
- EXIT-MCS
- LIS
- Dead

### Status at 12 months post-onset (linked with the CRS-R score):

- VS/UWS
- MCS
- EXIT-MCS
- LIS
- Dead

### Status at 24 months post-onset (linked with the CRS-R score):

- VS/UWS
- MCS
- EXIT-MCS
- LIS
- Dead

### Status at the time of the release of the expertise center:

- VS/UWS
- MCS
- EXIT-MCS
- LIS
- Dead



# CRF – Medical information

## **Tracheotomy**

had (yes / no)  
on admission (yes / no)  
at the release (yes / no)

## **Gastrostomy**

had (yes / no)  
on admission (yes / no)  
at the release (yes / no)

## **MRSA, infection**

had (yes / no)  
on admission (yes / no)  
at the release (yes / no)

# CRF – Hospitalization flow

**Date on injury:** mm/dd/yyyy

**Hospital:** List of hospital

**Department:**

- **EXPERTISE CENTER**

**Date hospitalization request in the expertise center:** mm/dd/yyyy

**Date admission in the expertise center:** mm/dd/yyyy

**Expertise center name:** List of expertise centers

- **NURSING HOME**

**Date hospitalization request in the nursing home:** mm/dd/yyyy

**Date admission in the nursing home:** mm/dd/yyyy

**Nursing home:** List of nursing home

- **HOME**

**Date hospitalization request at home:** mm/dd/yyyy

**Date admission at home:** mm/dd/yyyy