



Human Brain Project

Seminar on Data Governance and Informed Consent

Informed consent and coma patients

European Institute for Theoretical Neuroscience (EITN), Paris

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Belgium



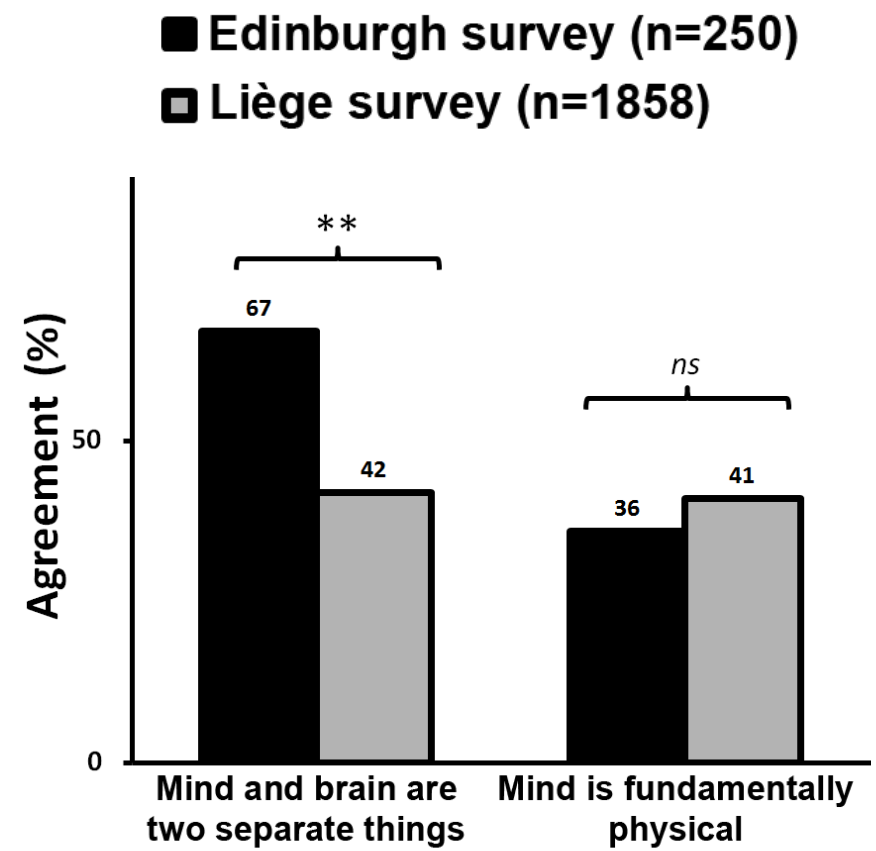
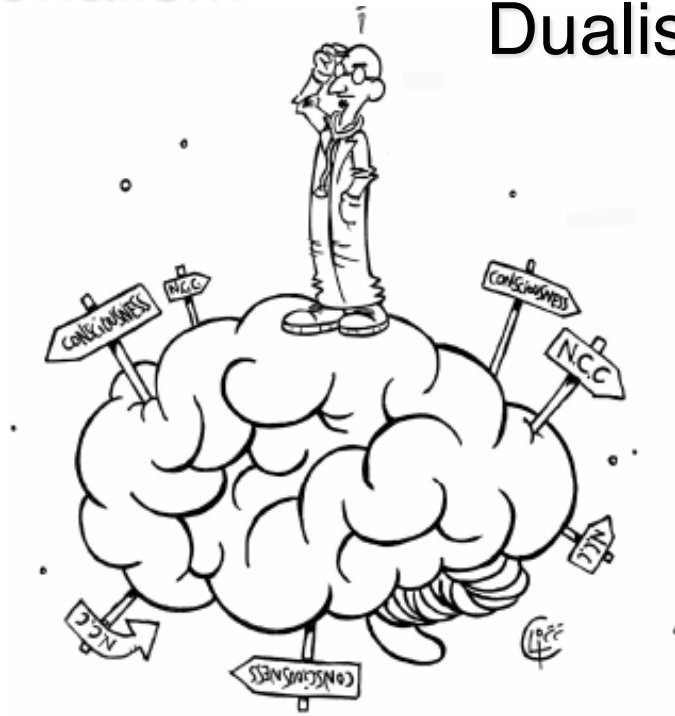
James S. McDonnell Foundation



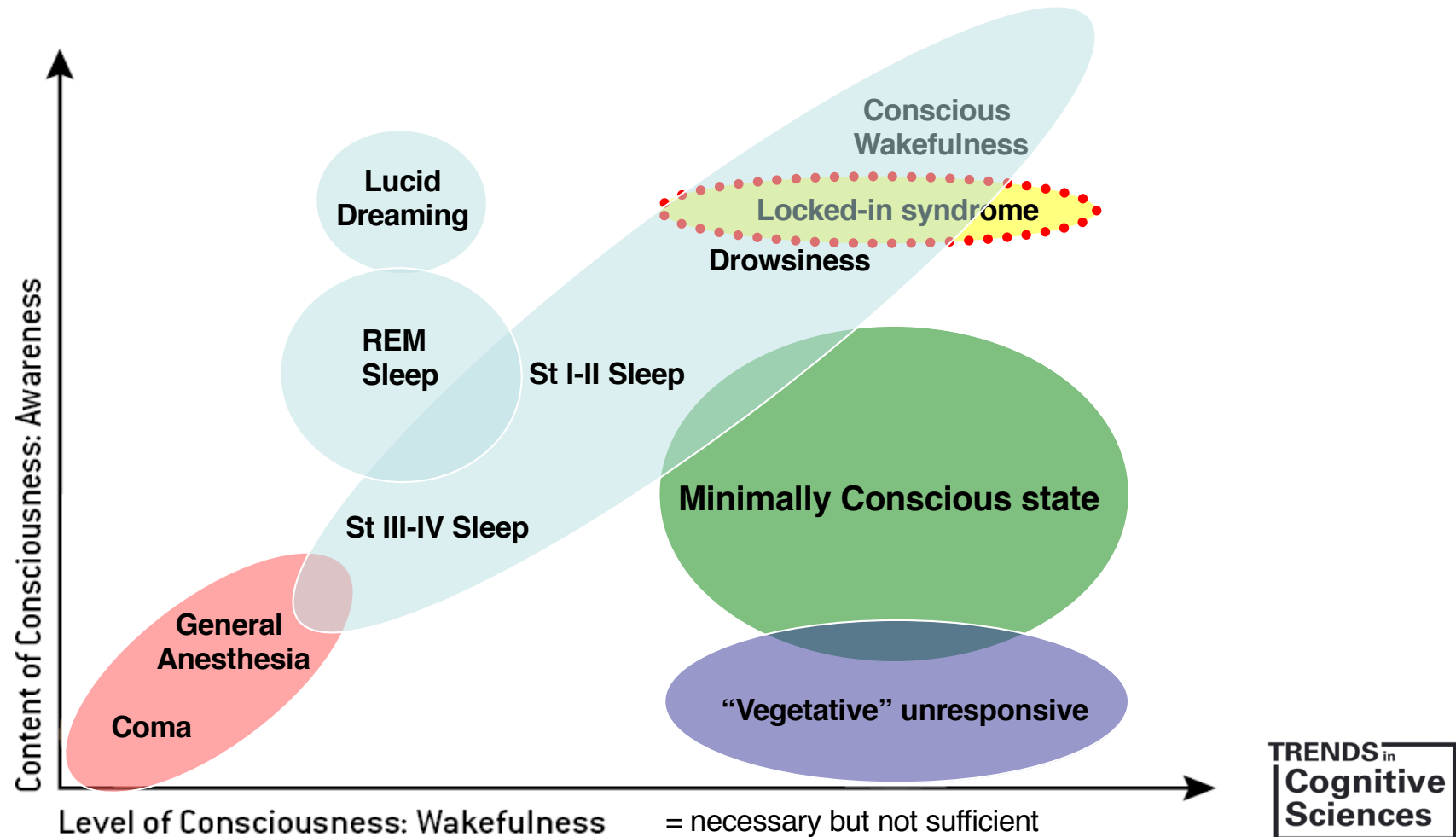
What is Consciousness?



Functionalism
Materialism
Dualism



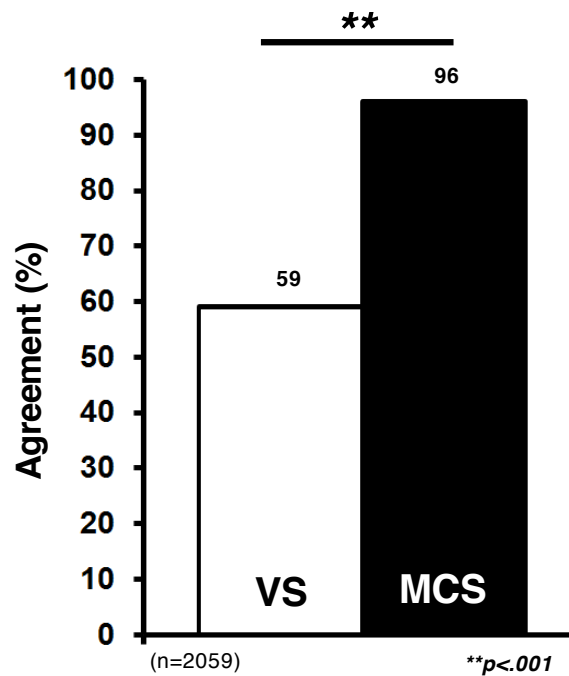
A clinical definition



Do they feel pain?



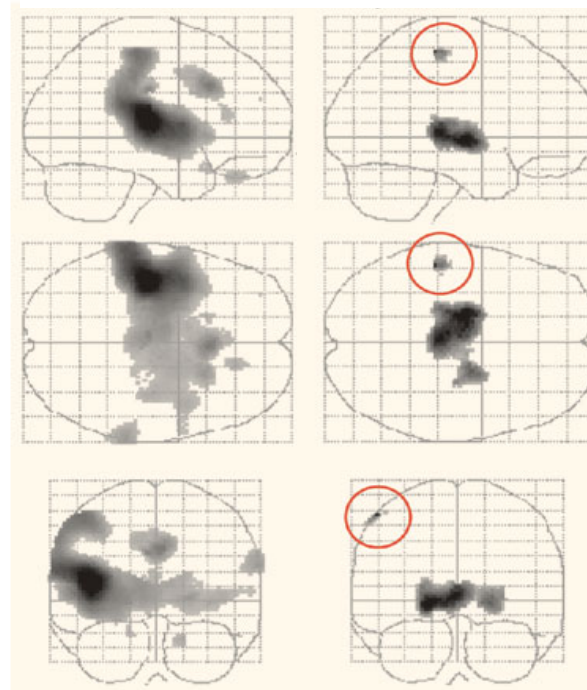
Do you think patients in a ...
can feel pain?



Demertzi et al, *Prog Brain Res* 2009
Demertzi & Racine et al, *Neuroethics* 2012

Unresponsive wakefulness syndrome

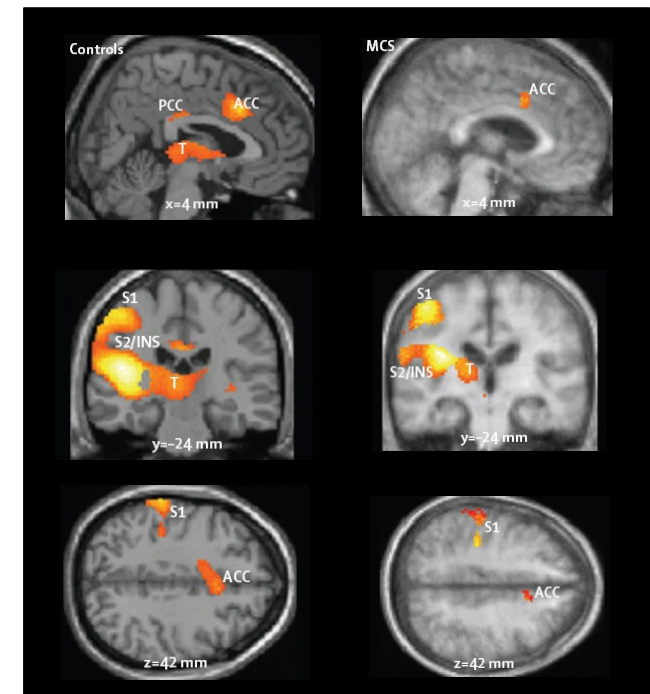
Healthy controls UWS patients



Laureys et al., *Neuroimage* 2002

Minimally conscious state

Healthy controls MCS patients



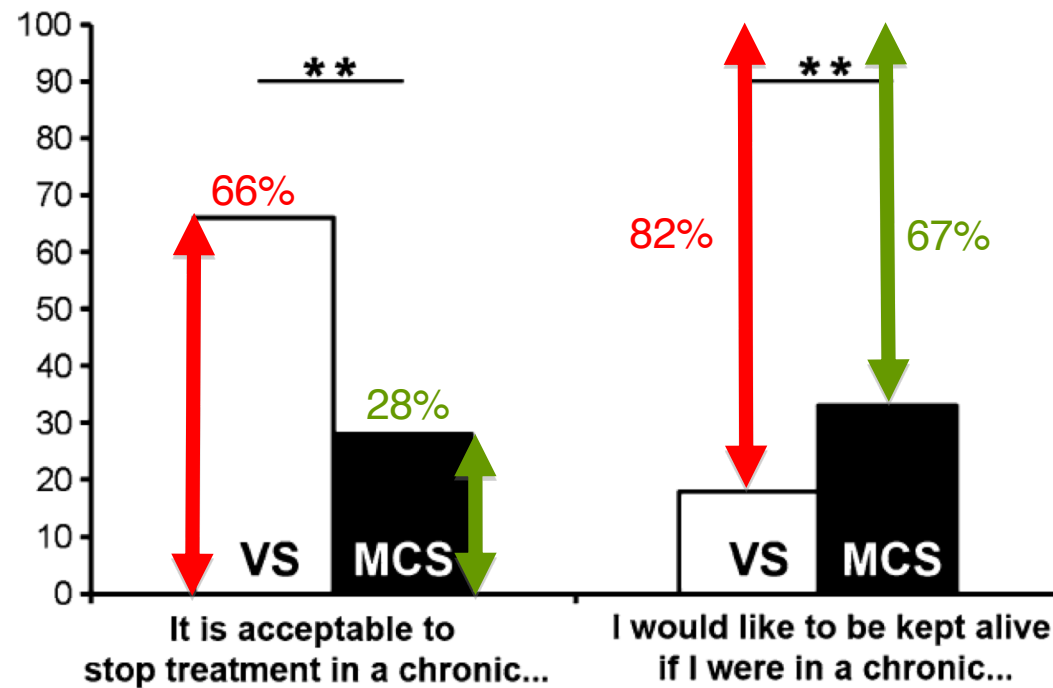
Boly et al, *Lancet Neurol* 2008

End-of-life?



- VS worse than death for the patient: 55%
- VS worse than death for their families: 80%
- MCS worse than VS for the patient: 54%
- MCS worse than VS for their families: 42%

2,475 medical professionals

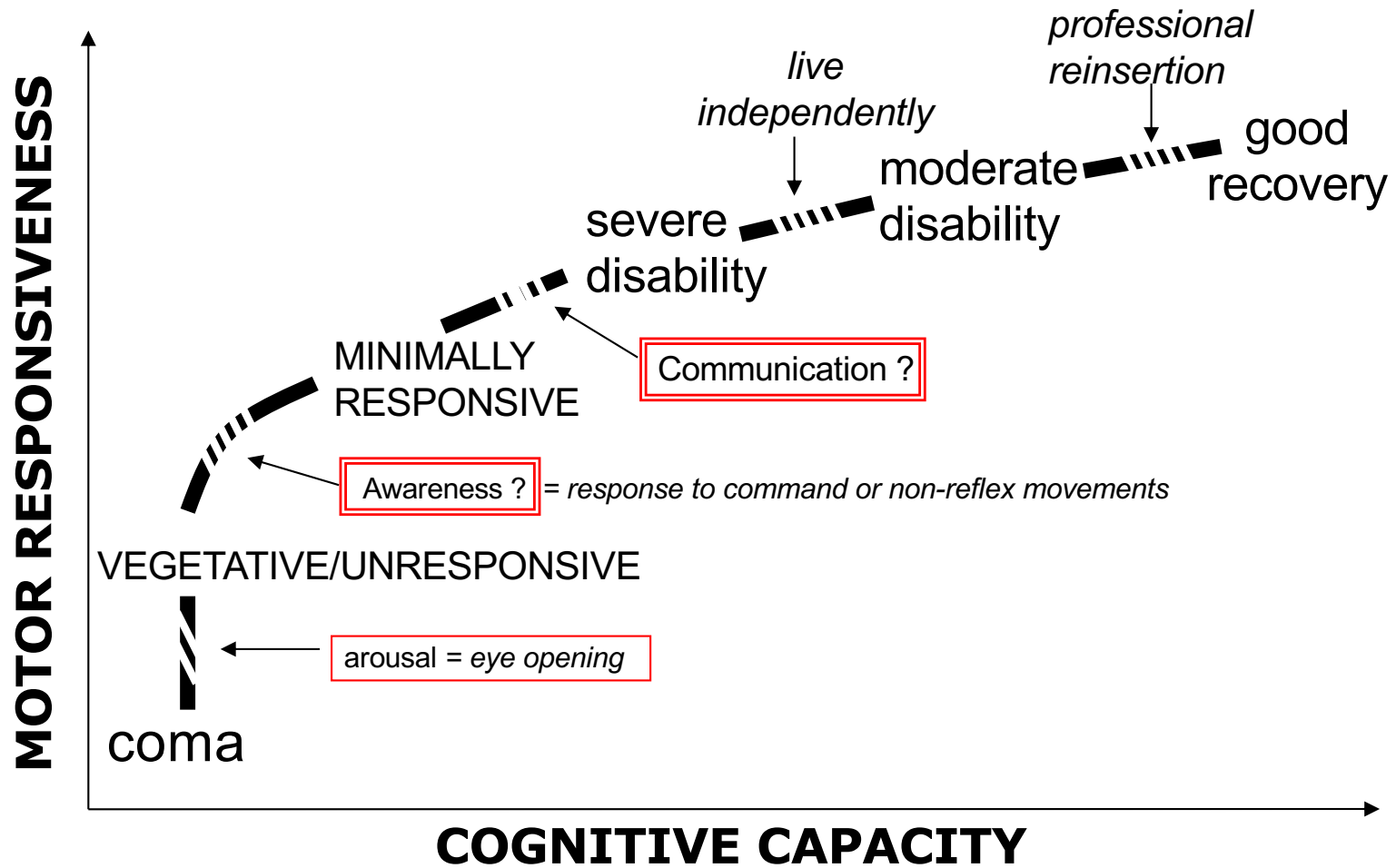


Behaviour



Terry Schiavo °1963,
vegetative 1990, † 2005 USA

Behavioural signs of C



Gold standard?



Standardized assessment

n=103 post-comatose patients

45 Clinical diagnosis of VS
18 Coma Recovery Scale MCS

↳ 40% misdiagnosed

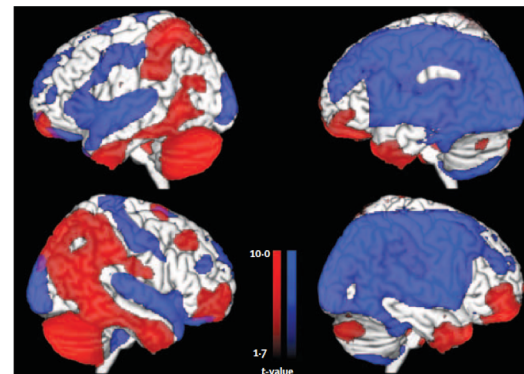
Schnakers et al, *Ann Neurol* 2006; *BMC Neurol* 2009

PET Neuroimaging

	Coma Recovery Scale-Revised results		
	UWS	MCS	Total
Clinical consensus diagnosis			
¹⁸F-FDG PET			
VS/UWS	24 (21%)	5 (4%)	29 (26%)
MCS	12 (11%)	71 (63%)	83 (74%)
Total	36 (32%)	76 (68%)	112 (100%)

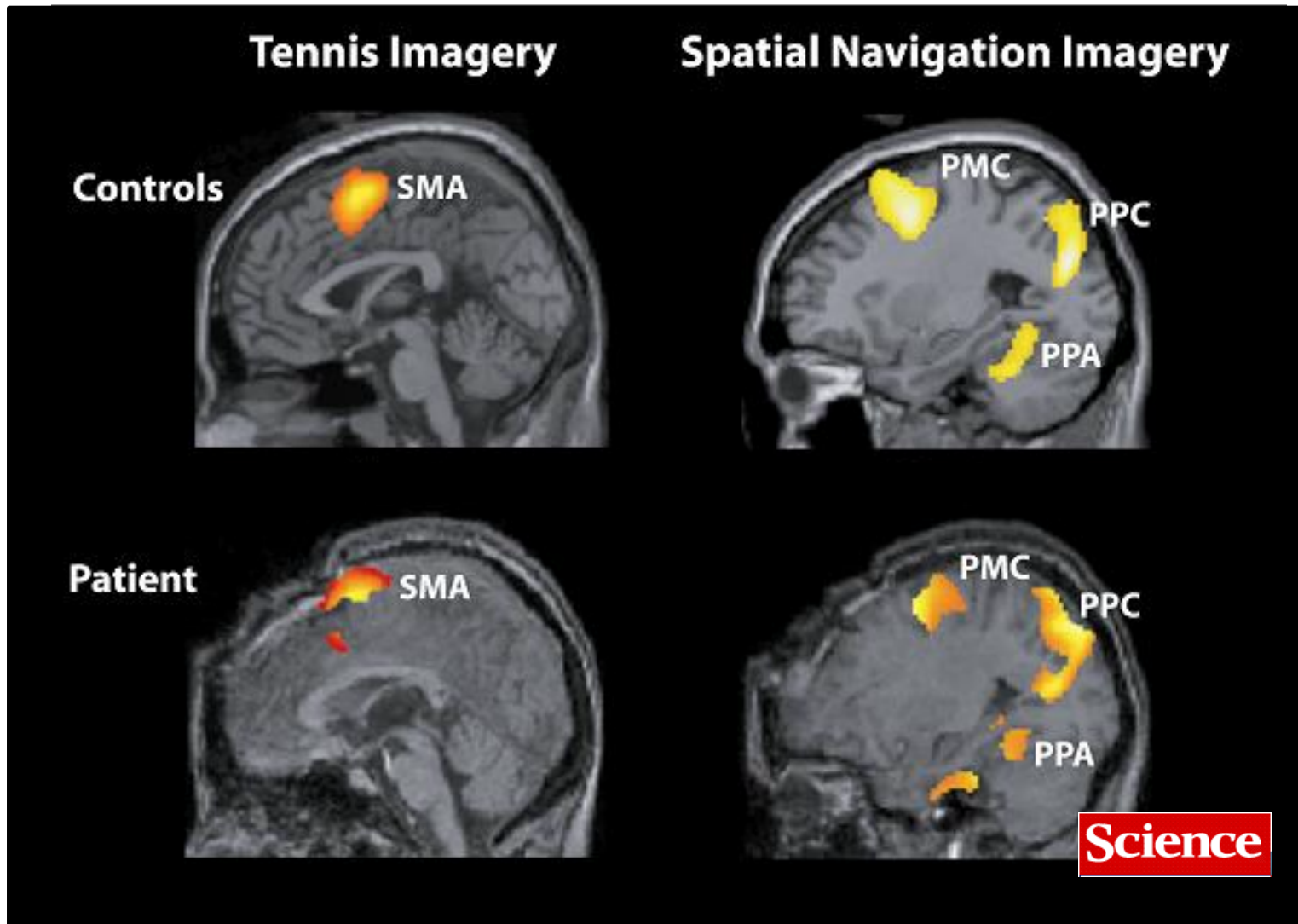
UWS=unresponsive wakefulness syndrome. MCS=minimally conscious state.

Table 2: Diagnostic results by modality



Stender & Gosseries et al, *Lancet* 2014

Neuroimaging: command following

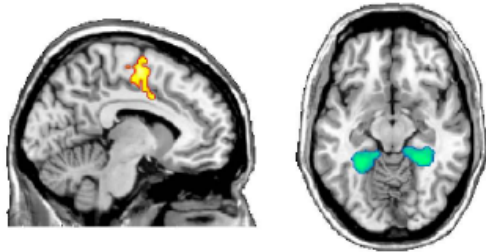


Neuroimaging: communication

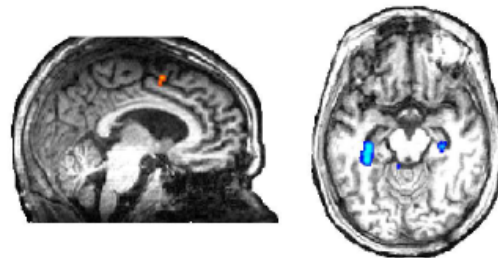


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Healthy Controls

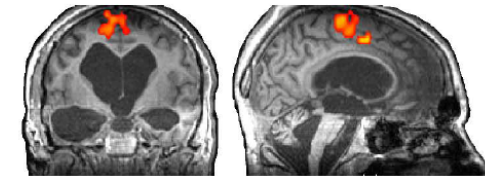


L25 TBI

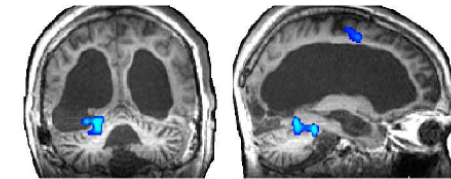


Imagine **Tennis** to answer 'YES'
Imagine **Navigating** to answer 'NO'

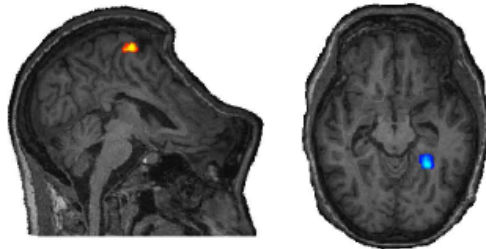
Is your father's name Alexander ?



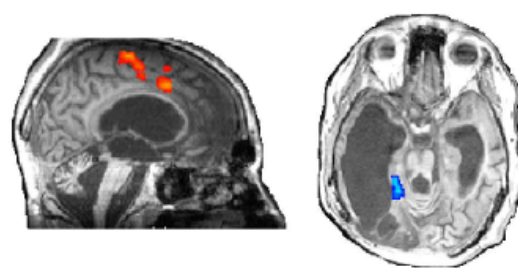
Is your father's name Thomas ?



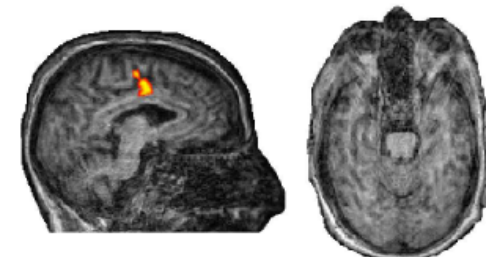
C04 TBI



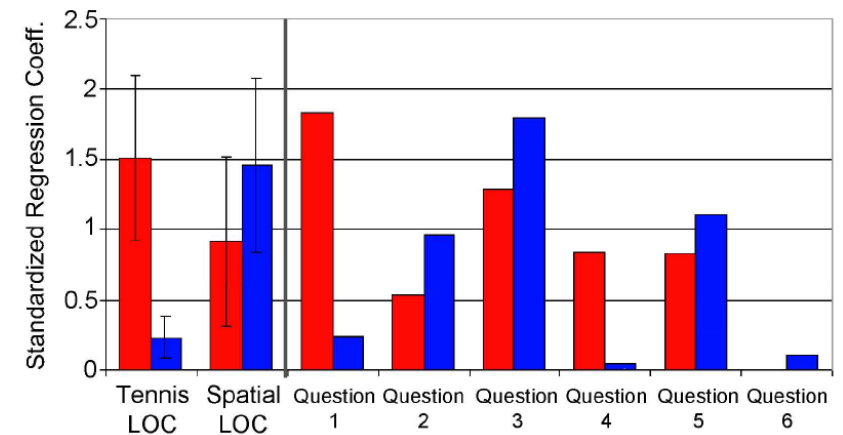
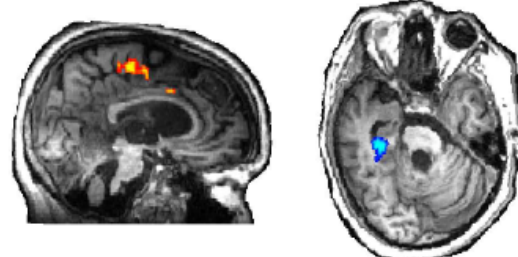
L23 TBI



C06 TBI



L22 TBI



Electrophysiology paradigms



“MOVE YOUR FOOT”

“MOVE YOUR HAND”



HEALTHY
CONTROL
SUBJECT



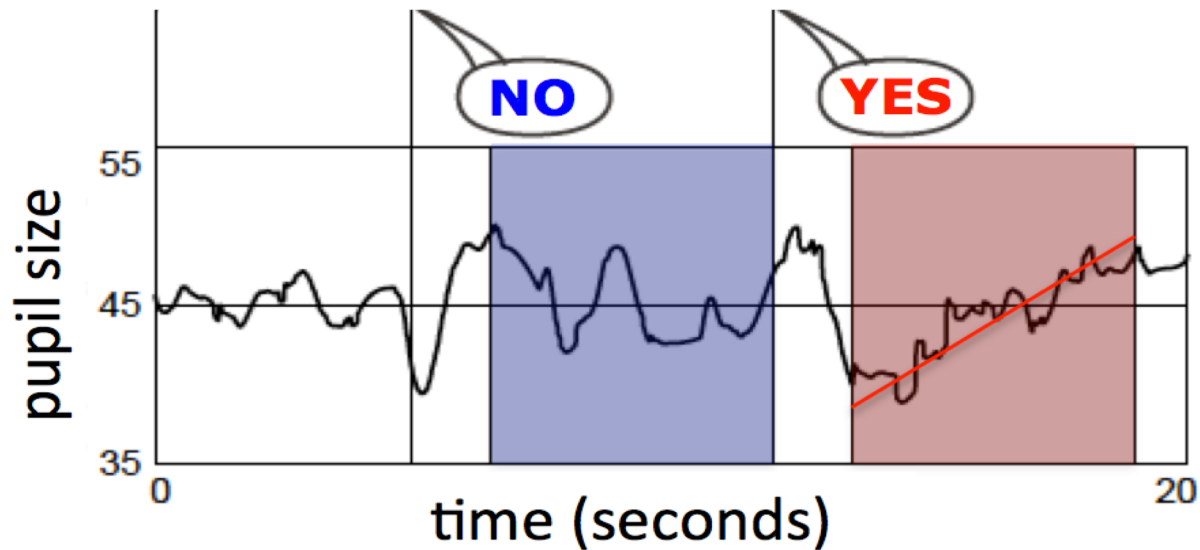
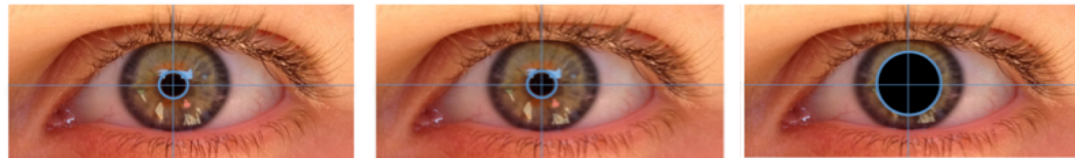
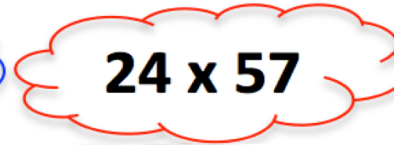
“VEGETATIVE”
UNRESPONSIVE
PATIENT



Pupil-based



IS YOUR
NAME CLARA?



Current
Biology



The American Journal of Bioethics, 8(9): 3–12, 2008

Target Article

Neuroimaging and Disorders of Consciousness: Envisioning an Ethical Research Agenda

Joseph J. Fins, Weill Medical College of Cornell University*

Judy Illes, University of British Columbia*

James L. Bernat, Dartmouth Medical School**

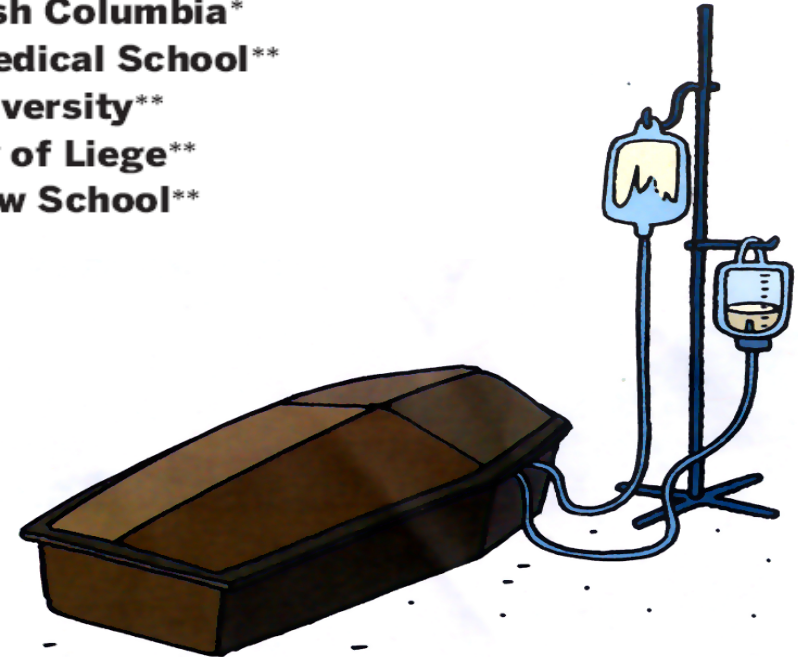
Joy Hirsch, Columbia University**

Steven Laureys, University of Liege**

Emily Murphy, Stanford Law School**

*Co-lead authors.

**Equal authors in alphabetical order.

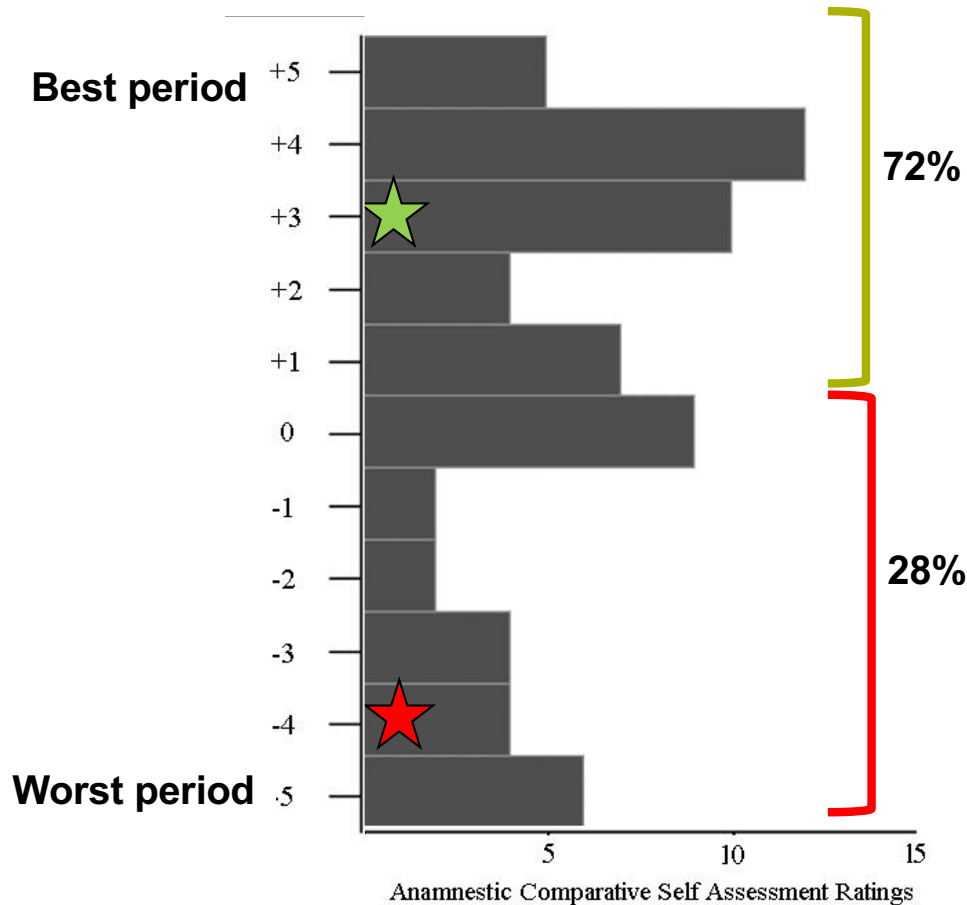


Balancing costs-benefits

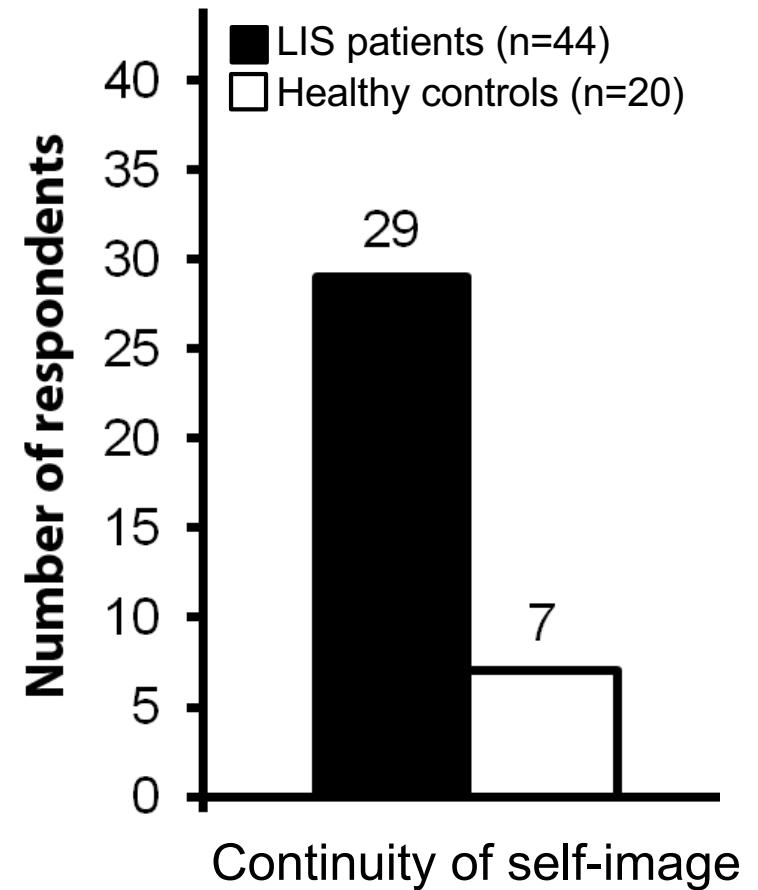


Results of Tests	Beneficial Effects	Harmful Effects
- brain activity than neurological examination	Relatives: decisions to limit life-sustaining treatment	Relatives: may lose hope, purpose, and meaning in life
+ brain activity than neurological examination	Clinical management: may be intensified by the chance of further recovery	Relatives: false hopes
Same as neurological examination	Clinicians & relatives: may be affirmed in their decision about the level of treatment	Clinicians & relatives: may be disappointed & treatment cost/effectiveness may be poor

Benefit for patients?



Bruno et al, *Br Med J Open* 2011



Nizzi & Demertzi et al, *Conscious & Cogn* 2012

QoL factors



Third vs. first-person perspective

n=65 LIS patients
time in LIS: 1-28 yrs

Table 3 Significant associations between happiness status and variables identified by the univariate analyses (marked by an asterisk in table 2)

	Odds ratio	SE	Z score	p> z	95% CI
Duration in LIS*	1.5	0.2	2.71	0.007	1.1 to 2.0
Speech production	20.47	24.87	2.48	0.013	1.89 to 221.45
Anxiety	0.19	0.15	-2.14	0.032	0.04 to 0.87

*Odds ratio per year in LIS.
LIS, locked-in syndrome.

58% : no resuscitation

7%: euthanasia wishes

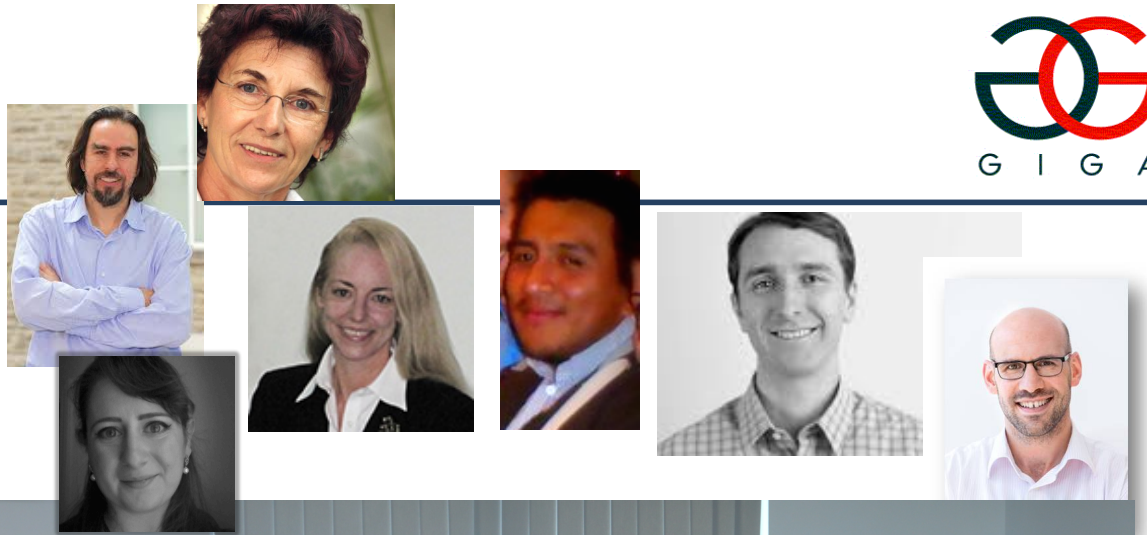
Conclusions



- Communication is essential to evidence awareness
- Patients can reveal their awareness with brain-computer interfaces
- Communicating patients can rate their QoL
- So far, these work as proof of concepts



What is needed to get standardized and legally valid?



Coma Science Group & PICNIC Lab

The departments of Neurology and Radiology in Liège and Paris

...and mostly patients and their families!



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