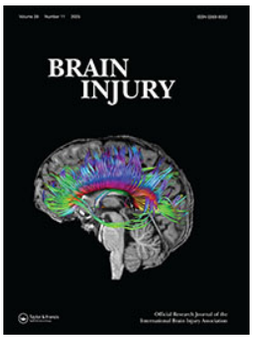

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RESEARCH ARTICLE

Centers for patients with prolonged disorder of consciousness: a preliminary international map

Simona Ferioli[a], Caroline Schnakers[b], Alfonso Magliacano[c], Nathan Zasler[d], Cecilia Ismari[b], Rita Formisano[e], Olivia Gosseries[f], Petra Maurer-Karattup[g], Erika Molteni[h], Brooke Murtaugh[i], Beth Slomine[j], Aurore Thibaut[f], and Anna Estraneo[c]

[a]Department of Neurology and Rehabilitation Medicine, University of Cincinnati, Cincinnati, Ohio, USA; [b]Research Institute of Casa Colina Hospital and Centers for Healthcare, Pomona, CA, California, USA; [c]IRCCS Fondazione Don Carlo Gnocchi, Florence, Italy; [d]Department of Physical Medicine and Rehabilitation, Virginia Commonwealth University, Richmond, Virginia, USA; [e]IRCCS Fondazione Santa Lucia, Rome, Italy; [f]Coma Science Group, University Hospital of Liege, Liege, Belgium; [g]Department of Neuropsychology, Fachkrankenhaus Hospital, Neresheim, Germany; [h]Department of Biomedical Engineering and Imaging Sciences, King's College, London, UK; [i]Department of Rehabilitation Programs, Madonna Rehabilitation Hospitals, Lincoln, Nebraska, USA; [j]Department of Neuropsychology, Kennedy-Krieger Institute John Hopkins University, Baltimore, Maryland, USA

ABSTRACT

Introduction: Prolonged disorders of consciousness (pDoC) patients require specialized care to support recovery and manage complications, but information regarding the location and scope of dedicated centers is lacking. We conducted an international survey among specialists in this field to identify centers serving this population and developed a publicly available online resource for care providers, families, stakeholders, and neuroscientists involved in the care and management of people with pDoC.

Methods: A 17-question survey was distributed online between May 2022 and May 2024 to IBIA (International Brain Injury Association) members and sent to other professional societies involved in pDoC care. Responses were then grouped and analyzed based on geographic regions (Europe/UK, USA, and others).

Results: We collected data from 153 centers across 35 countries. Most centers indicated they accepted patients of all etiologies and ages, with regional differences in length of stay, access pathways, and discharge criteria. Nearly all centers were reported to provide caregiver training and counseling. A link to the map with centers contact information had been published on the IBIA website (https://www.internationalbrain.org/membership/ibia-special-interest-groups/disorders-of-consciousness-special-interest-group/disorders-of-consciousness-programs-project).

Discussion and conclusions: Our survey allowed the creation of the first preliminary international map of centers specialized in pDoC available online to families and providers. Future efforts are needed to identify other relevant centers of care, increase geographical representation, and foster collaboration to improve care accessibility and outcomes for patients with pDoC.

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Disorders of consciousness; post-acute care; coma; rehabilitation; caregiver; brain injury

Introduction

Survivors of severe acquired brain injury may present with a prolonged disorder of consciousness (pDoC) that persists after the acute injury phase (1). Substantial progress has been made over the past two decades in detecting, predicting, and promoting recovery of consciousness in patients with pDoC (1,2). Recent guidelines (3) have recommended managing these complex patients in dedicated care units to detect and enable recovery of consciousness as well as prevent and treat possible complications. Over the past decade, multiple studies have demonstrated the high probability of recovery of consciousness after severe brain injury, even occurring weeks to months post-injury (4,5). Furthermore, patients with pDoC that access specialized post-acute rehabilitation demonstrate improved outcomes compared to those who do not (6). The rare but not exceptional possibility of recovery of consciousness in the weeks to months after injury suggests careful and expert long-term monitoring of the clinical evolution of these patients (4). Unfortunately, healthcare providers and family caregivers often lack sufficient information on how and where to access specialized care when it is time to discharge from the intensive care unit or acute care setting. As a result, patients with pDoC may remain in acute care settings not equipped for early rehabilitation or may be directly transferred to long-term care facilities without access to treatment programs knowledgeable in serving the pDoC population (7). This critical issue increases the psychological distress of family members who are already strained by the severity of their loved one's clinical condition including its multidimensional implications on the family unit (7,8). To help fill this gap, the International Brain Injury Association Disorder of Consciousness Special Interest Group (IBIA pDoC-SIG) tasked itself with the development of an international map of post-acute care centers serving patients with pDoC. This resource has been made freely available online to the

CONTACT Simona Ferioli simona.ferioli@uc.edu Department of Neurology and Rehabilitation Medicine, University of Cincinnati, Cincinnati, OH, USA
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international community of care providers, families, stakeholders, and policy makers. For this purpose, a global online survey has been launched to identify as well as characterize the profile of centers that offer specialized care to patients with pDoC. An additional explorative aim of our project was to preliminarily investigate possible differences of the management of patients with pDoC across geographical areas with different health systems.

Materials and methods

A questionnaire was collaboratively designed during several virtual meetings attended by IBIA pDoC-SIG members. The final version of the survey included 17 items and took approximately 10 min to complete. Most items consist of closed-ended questions with single or multiple-choice answers. A few open-ended questions were also included to allow respondents to expand upon answers and to obtain more detailed information (see the survey in Appendix). Respondents could choose more than one answer and/or leave questions unanswered.

The survey was launched in May 2022 via Survey Monkey (SurveyMonkey Inc., SanMateo, California, USA; www.SurveyMonkey.com). The link has remained available on the IBIA website and sent to professional associations collaborating with IBIA and involved with pDoC diagnosis and care, as well as to academic and private centers known for their leadership in pDoC care and research. This preliminary data set was collected 2 years after launch, in May 2024. Respondents' answers were anonymous. This anonymous survey has been determined to be exempt from full review by the Institutional Review Board (IRB) of Casa Colina Hospital and the Centers for Healthcare, given the nature of the study.

Data was exported to Excel (Microsoft, WA, United States) and checked to exclude duplicates, in case of more than one provider answering from the same center. Center addresses were cross-matched and verified with available online information to make sure the correct contact information was up to date.

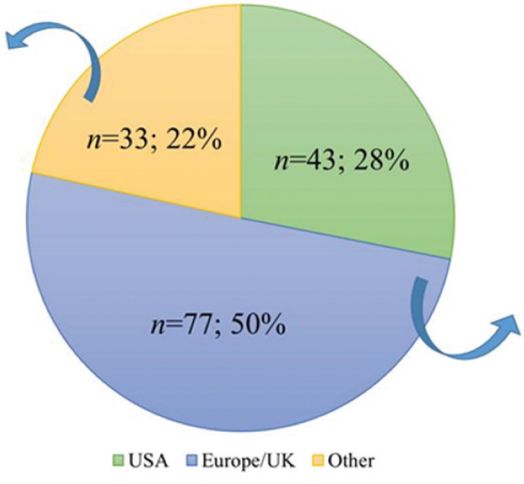
Responses and omissions were calculated for each question. Not all respondents answered all the questions, and results are, therefore, reported based on total responses for each question. The proportion of responses for all answers to closed-ended questions were calculated, whereas responses to open-ended questions were considered, and reported in the discussion, only to get a more accurate picture of each phenomenon.

In order to explore possible differences in the management of patients with pDoC, data were grouped as a function of respondents' demographics into three geographical areas (Europe, USA, and other, which included Canada, Asia–Pacific, Africa, and South America). Percentages of responses were compared between Europe and USA through χ^2 tests. This statistical comparison was limited between the USA and Europe as these were the regions with a higher number of respondents and with known difference in healthcare organization. The level of significance was set at 0.05. All analyses were performed using IBM SPSS v.25 (IBM Corp., Armonk, New York, USA).

Results

One hundred and fifty-three rehabilitation providers, self-identified as working in pDoC centers, responded to the survey. Most were in Europe (77) (with 44 centers from Italy), 43 were in the USA and 33 from other countries (21 in total) (Figure 1). Centers were identified geographically and cross-referenced with their public addresses and phone numbers, creating an online map hosted within the IBIA website: https://www.google.com/maps/d/edit?mid=1lpRu92tElS-zikW6mOoTO-qZl9G-y70&ll=0.5764458921695166%2C0&z=2. The Comparison of responses between USA and Europe is reported in Table 1.

Country	n
Argentina	2
Australia	1
Brazil	1
Canada	4
Chile	1
Columbia	1
Cuba	1
El Salvador	1
Ethiopia	1
India	2
Israel	1
Malaysia	3
Mexico	1
Nepal	1
Nigeria	3
Republic of Singapore	2
Russia	4
South Sudan	1
Taiwan	1
Turkey	1



Country	n
Belgium	5
Denmark	4
Finland	1
France	1
Germany	1
Ireland	1
Italy	44
Moldova	2
Netherlands	5
Norway	3
Portugal	1
Slovenia	1
Spain	3
Switzerland	1
United Kingdom	4

Figure 1. Frequencies and percentage of respondents as a function of the geographical origin.

Table 1. Results of the survey with responses to each question as a function of the geographical area.

Question	Overall sample	USA	Europe/UK	*p*
1. We accept patients with the following diagnoses:	***n* = 153**	***n* = 43**	***n* = 77**	
TBI only	2.0%	2.3%	1.3%	0.674
Vascular only	0%	.	.	.
Post-anoxic/hypoxic only	0%	.	.	.
TBI + Vascular	1.3%	0%	1.3%	0.453
TBI + Post-anoxic/hypoxic	0.7%	0%	0%	.
Vascular + Post-anoxic/hypoxic	0%	.	.	.
Any	96.1%	97.7%	97.4%	0.927
2. We admit patients with the following pDoC subgroups:	***n* = 148**	***n* = 41**	***n* = 75**	
VS/UWS only	0%	.	.	.
MCS *minus* only	0%	.	.	.
MCS *plus* without communication only	0%	.	.	.
MCS *plus* with intentional communication only	4.1%	4.9%	4.0%	0.824
MCS *minus* and *plus* only	14.2%	24.4%	5.3%	0.003
MCS *plus* only	4.1%	4.9%	5.3%	0.916
Any	77.7%	65.9%	85.3%	0.015
3. We treat the following age patients with pDoC:	***n* = 150**	***n* = 41**	***n* = 76**	
Any	22.0%	19.5%	15.8%	0.610
0–12 years	0%	.	.	.
0–16 years	4.6%	0%	5.3%	0.135
0–65 years	10.0%	17.1%	9.2%	0.211
17–65 years	4.0%	7.3%	1.3%	0.088
≥13 years	15.3%	12.2%	15.8%	0.599
≥17 years	42.7%	41.5%	51.3%	0.309
≥65 years	0%	.	.	.
4. We admit international patients with a pDoC:	***n* = 150**	***n* = 40**	***n* = 77**	
Yes	38.7%	40.0%	29.9%	0.270
Only case by case basis	47.3%	47.5%	55.8%	0.391
No	14.0%	12.5%	14.3%	0.790
5. We admit and care for patients who require mechanical ventilation:	***n* = 149**	***n* = 39**	***n* = 77**	
Yes	54.4%	51.3%	50.6%	0.949
No	45.6%	48.7%	49.4%	0.949
6. We provide the following level(s) of care for patients with pDoC:	***n* = 150**	***n* = 41**	***n* = 77**	
Any	24.7%	22.0%	22.1%	0.987
Acute only	9.3%	19.5%	3.9%	0.005
Post-acute only	16.0%	7.3%	24.7%	0.021
Chronic (>1 year) only	2.7%	2.4%	2.6%	0.958
Acute + post-acute	29.3%	34.1%	26.0%	0.351
Post-acute + Chronic	17.0%	14.6%	20.8%	0.414
7. We provide outpatient/day hospital care for pDoC patients:	***n* = 150**	***n* = 40**	***n* = 77**	
Yes	62.0%	62.5%	55.8%	0.489
No	38.0%	37.5%	44.2%	0.489
8. What is the mean length of stay of patients admitted in a pDoC?	***n* = 98**	***n* = 16**	***n* = 61**	
Any	3.1%	0%	1.6%	0.606
Up to 2 weeks	20.4%	37.5%	11.5%	0.013
>2 weeks but <1 year	55.1%	43.8%	63.9%	0.143
>2 weeks	13.3%	12.5%	16.4%	0.702
>1 year	5.1%	6.3%	4.9%	0.831
<1 year	3.1%	0%	1.6%	0.606
9. Length of stay is determined by the following:	***n* = 150**	***n* = 40**	***n* = 77**	
All	10.0%	15.0%	9.1%	0.335
Functional progress as assessed by standardized measure(s)	26.7%	5.0%	29.9%	0.002
Insurance	0.7%	2.5%	0%	0.163
National system regulation	4.0%	0%	7.8%	0.070
Functional progress + Insurance	17.3%	55.0%	2.6%	<0.001
Functional progress + National system regulation	16.0%	0%	27.3%	<0.001
Insurance + National system regulation	2.0%	0%	1.3%	0.469
Other	4.7%	5.0%	5.2%	0.964
10. How are patients admitted to your center?	***n* = 151**	***n* = 41**	***n* = 77**	
All	38.4%	61.0%	20.8%	<0.001
Physicians' referral	3.3%	2.4%	1.3%	0.648
Transfer from acute care institution	16.6%	2.4%	28.6%	0.001
Family outreach	0%	.	.	.
Physicians' referral + Transfer from acute care institution	21.9%	9.8%	31.2%	0.009
Physicians' referral + Family outreach	2.6%	4.9%	1.3%	0.240
Transfer from acute care institution + Family outreach	4.0%	2.4%	5.2%	0.479
Other	2.6%	2.4%	1.3%	0.648

(*Continued*)

Table 1. (Continued).

Question	Overall sample	USA	Europe/UK	*p*
11. Do your providers have specialized training and experience in assessment and management of patients with pDoC as defined in Giacino et al. (3)?	***n* = 151**	***n* = 41**	***n* = 77**	
Yes	72.8%	87.8%	68.8%	0.023
No	27.2%	12.2%	31.2%	0.009
12. Does your program follow any published pDoC guidelines for the diagnosis, prognosis and/or treatment?	***n* = 149**	***n* = 40**	***n* = 76**	
Yes	71.8%	80.0%	71.1%	0.296
No	28.2%	20.0%	28.9%	0.296
13. Do you actively involve caregivers in patient's diagnosis, prognosis and/or treatment?	***n* = 141**	***n* = 39**	***n* = 71**	
Yes	97.9%	100%	97.2%	0.290
No	2.1%	0%	2.8%	0.290
14. Are family/caregiver education and counseling services provided as a core element of your program?	***n* = 139**	***n* = 38**	***n* = 71**	
Yes	88.5%	89.5%	87.3%	0.741
No	11.5%	10.5%	12.7%	0.741
15. Do families and patients associations/support groups collaborate with your center?	***n* = 138**	***n* = 37**	***n* = 71**	
Yes	66.7%	78.4%	70.4%	0.376
No	33.3%	21.6%	29.6%	0.376

Questions 1–3, 6, and 8–10 had multiple-choice answers. Data are reported as percentages and univariate statistics are based upon the $\chi 2$ test. Significant differences across the groups are reported in bold. Abbreviations: pDoC = Disorders of Consciousness; MCS = Minimally Conscious State; TBI = Traumatic Brain Injury; UK = United Kingdom; USA = United States of America; VS/UWS = Vegetative State/Unresponsive Wakefulness Syndrome.

Etiology and diagnosis

Most respondents ($n = 147/153$; 96%) shared that they admitted patients with any etiology leading to pDoC, with only 2% ($n = 3$) of the respondents answering that they admitted only to patients with traumatic brain injury (TBI). Similarly, most centers ($n = 115/148$; 78%) responded that they accepted all pDoC diagnoses, whereas 14% ($n = 21/148$) only admit patients in the minimally conscious state (MCS). This was more frequent in the USA ($n = 10/41$; 24%) compared to Europe ($n = 4/75$; 5%; $p = 0.003$).

Demographic and clinical criteria

Age was not an exclusive admission criteria for several centers. Indeed, 65% ($n = 97/150$) of responses indicated that centers admit patients of any age. Only 5% ($n = 7/150$) responded that they are dedicated exclusively to pediatric pDoC (i.e., 0–16 years).

Thirty-nine percent (39%) ($n = 58/150$) of centers admitted patients with pDoC from outside their country with 14% ($n = 21/150$) responding that they did not. Forty-seven percent (47%) ($n = 71/150$) answered that they admitted 'international' patients with pDoC on a case-by-case basis.

Mechanical ventilation

Fifty-four percent ($n = 81/149$) of centers answered that they admitted patients on mechanical ventilation. The question did not specify the patient's tracheostomy status or level of mechanical support.

Access modalities

Seventeen percent ($n = 25/151$) answered they receive patients directly from acute care wards, 22% ($n = 33/151$) from acute care institutions after physician's referral, and 7% ($n = 10/151$) indicated family outreach and external referral or transfer from acute centers as admission criteria. About one third ($n = 58/151$; 38%) answered that they accept patients from all access modalities. This was more frequent in USA ($n = 25/41$; 61%) compared to Europe where patients are mostly admitted by transfer from acute care institutions ($n = 16/77$; 21%) ($p < 0.001$).

Setting: When asked about the level of care, 9% ($n = 14/150$) of the centers responded that they only provide acute care (= up to 28 days), 16% ($n = 24/150$) only provide post-acute care (≥29-year), whereas 3% ($n = 4/150$) are chronic care facilities (= LOS > 1 year). However, most of the centers answered that they provide both acute and post-acute care ($n = 44/150$; 29%), and 25% ($n = 37/150$) provide any level of care (acute, post-acute, and chronic). Acute care was more represented in USA ($n = 8/41$; 19%) with respect to Europe ($n = 3/77$; 4%; $p = 0.005$), whereas post-acute care was more represented by European centers ($n = 19/77$; 25%) compared to the USA ($n = 3/41$; 7%; $p = 0.021$). In addition, 62% ($n = 93/150$) centers across the regions shared that they provide some forms of additional outpatient/day hospital pDoC care.

Length of stay (LOS)

Most of the centers ($n = 54/98$; 55%) responded that LOS is longer than 2 weeks but shorter than 1 year. Only 5% ($n = 5/98$) indicated that LOS could be over 1 year, whereas 20% ($n = 20/98$) answered that their LOS is shorter than 2 weeks. Shorter

LOS was less frequent in Europe ($n = 7/61$; 11%) than in the USA ($n = 6/16$; 37%; $p = 0.013$).

In most cases ($n = 40/150$; 27%), the LOS was determined by the patient's functional progress as assessed by standardized measures. In some cases, insurance ($n = 26/150$; 17%) or national system regulations ($n = 24/150$; 16%) influenced LOS in addition to the patient's functional progress (appendix Table 1). The role of insurance on LOS was noted to be more frequent in the USA ($n = 22/40$; 55%) than Europe ($n = 2/77$; 3%; $p < 0.001$)

Prolonged disorders of consciousness programs

The majority of respondents (73%; $n = 110/151$) stated that they have specialized training and/or experience in working with patients with pDoC, especially in the USA ($n = 36/41$; 88%) when compared with Europe ($n = 53/77$; 69%; $p = 0.023$). Most centers (72%; $n = 107/149$) also responded that their pDoC care programs follow published pDoC guidelines (Appendix).

Role of the caregivers and associations

Nearly all centers ($n = 138/141$; 98%) involved caregivers and provided them with specialized training and counseling ($n = 123/139$; 88%). In most cases ($n = 92/138$; 67%), centers collaborated with associations and/or support groups.

Discussion

This is the first international map of centers specialized in working with patients with pDoC developed and available online to providers and caregivers. The present survey identified over 150 centers around the world who shared similar features regardless of country of origin and healthcare system. Although the collected data did not cover many geographical areas, an exploratory statistical analysis revealed preliminary similarities and differences among centers. The injury etiology and age range did not appear to be an admission exclusion in most centers across the world. Nearly all centers responded that they involved families and provided training, stressing the need for caregiver support and engagement in patient care.

We found some specific differences in the organizations of care units among USA and Europe that could reflect the economic resources and regulations of the national health systems. Shorter LOS (<2 weeks) was more present in the US compared to Europe, with Italy being the biggest driver of this difference. LOS from 2 weeks to 1 year was more frequently reported in Europe. Insurance was mentioned as a criterion for discharge more frequently in USA centers, while national system regulations as a driver of discharge criteria were reported more in Europe.

Physician referral and family outreach as criteria for access were mentioned more often in the USA. Most centers reported dedicated pDoC programs, consistent with the American Academy of Neurology guidelines that recommended 'referral to specialized, interdisciplinary rehabilitation once medical stability is achieved' (1). A skilled multidisciplinary team is required for managing the high complexity of these patients, making an accurate clinical assessment of conscious and disability levels (9), and providing an appropriate prognosis (2,9). Moreover, these patients have an elevated risk of developing clinical complications (e.g., epilepsy and severe infections) that can negatively impact clinical outcomes (4). Only 10% of American centers answered that they do not have specialized training, vs 31% of Europe.

The present study has several limitations. First, the survey was distributed through professional society mailing lists and social media, and did not reach centers involved in pDoC outside these networks, especially in countries where such entities are not represented. Despite this limitation, the survey reached 35 countries with a large distribution in three areas across the world. Second, the definitions of acute and post-acute care for patients with pDoC are still debated (4,10) and may vary across countries and healthcare systems, not allowing for rigorous homogeneous comparisons. Future implementation and dissemination of the survey will be necessary to build a more exhaustive international map of the centers involved in the pDoC. In addition, the close-ended and multiple-choice answer formats led to incomplete or missing data, as it relies on the willingness and transparency of respondents. However, except for one question (i.e., n° 8: LOS, answered by 64% of respondents), all questions were answered by at least 90% of the total respondents.

Future directions

Notwithstanding the study limitations, this survey is the first attempt to develop an international map of clinical centers involved in the care pathway of patients with pDoC. The plan for the dissemination of this work included its presentation at the IBIA conference and congress, the continuous update of the online map, and the fostering of ongoing collaboration with scientific societies with expertise in this brain injury care with the goal of engaging additional clinical centers and ensuring a wider dissemination of this information. Additionally, the scientific community with expertise in pediatric population will be involved through IBIA members that have experience in pediatric pDoC. We also plan to involve stakeholders and policy makers from each country, as this map could serve as a preliminary census of facilities already activated to assess possible gaps or appropriateness in the distribution of clinical care centers for patients with pDoC in those geographical areas.

Conclusions

The importance of diagnosis and specialized care for patients with pDoC after severe brain injury has been increasingly recognized as crucial to support their recovery. Questions remain as to how patients might best access such care, who will provide such care, and where that care might best be provided (vs. where that care is currently provided). Several recent initiatives such as the IBIA pDoC SIG Congress and the ongoing Neurocritical Care Society Curing Coma Campaign (https://www.curingcoma.org) have identified pDoC care as an urgent problem across the world. Our survey represents one of the first attempts to locate and describe specialized

centers for adult and pediatric patients in an online format for providers and caregivers. Future work is required to provide country and center level detailed information to increase the collaboration and growth of the pDoC care community and facilitate clinical as well as research networking efforts.

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Disclosure statement

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ORCID

Caroline Schnakers http://orcid.org/0000-0003-1143-0658
Anna Estraneo http://orcid.org/0000-0001-6646-5626

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APPENDICES

(1) List of pDoC guidelines
(2) Survey template

List of pDoC guidelines reported by responders.

- Italian society of physical medicine and rehabilitation
- pDoC following Sudden Onset Brain Injury: National Clinical Guidelines. Royal College of Physicians of London
- European Academy of Neurology
- On the diagnosis of coma and other disorders of consciousness
- Practice guidelines update recommendations summary: Disorders of consciousness.
- National Institute on Disability, Independent Living and Rehabilitation Research
- Russian National guidelines

Survey Template

* 1. Contact Information

Name of Center	
Country	
Address	
Phone Number	
Website (if available)	

2. We accept patients with the following diagnoses: (check all that apply)

- [ ] Traumatic Brain Injury
- [ ] Vascular (strokes, intracranial hemorrhages)
- [ ] Post-anoxic/hypoxic
- [ ] Any neurological condition leading to a DoC

3. We admit patients with the following DoC subgroups: (check all that apply)

- [ ] Vegetative state / Unresponsive wakefulness syndrome
- [ ] Minimally conscious state (not responding to command yet)
- [ ] Minimally conscious state (responding to command but not communicating yet)
- [ ] Minimally conscious state (starting to communicate but not functionally yet)

4. We treat the following age patients with DoC: (check all that apply)

- [ ] 0-12
- [ ] 13-16
- [ ] 17-25
- [ ] 26-65
- [ ] >65

5. We admit and care for international patients with a DoC

6. We admit and care for patients who require mechanical ventilation.

7. We provide the following level(s) of care for patients with DoC: (check all that apply)

- [ ] Acute (28 days)
- [ ] Post-Acute (29 days - 1 year)
- [ ] Chronic (>1 year)

8. We provide outpatient/day hospital care for DoC patients.

9. What is the mean length of stay of patients admitted in a DoC? (check all that apply)

- [ ] Up to 2 weeks
- [ ] >2 weeks - 3 months
- [ ] >3 months - 1 year
- [ ] >1 year

10. Length of stay is determined by the following: (check all that apply)

- [ ] Functional progress as assessed by standardized measure(s)
- [ ] Insurance
- [ ] National system regulation
- [ ] Other (please specify)

11. How are patients admitted to your center? (check all that apply)

- [ ] Physicians' referral
- [ ] Transfer from acute care institution
- [ ] Family outreach
- [ ] Other (please specify)

12. Do your providers have specialized training and experience in assessment and management of patients with DoC as defined in the publication: "*Minimum Competency Recommendations for Programs That Provide Rehabilitation Services for Persons With Disorders of Consciousness: A Position Statement of the American Congress of Rehabilitation Medicine and the National Institute on Disability, Independent Living and Rehabilitation Research Traumatic Brain Injury Model Systems*" (Giacino et al. 2020)?

13. Does your program follow any published DoC guidelines for the diagnosis, prognosis, and/or treatment?

- Yes
- No

14. If yes, please note specific guideline:

15. Do you actively involve families/caregivers in patient´s diagnosis, prognosis, and/or treatment?

16. Are family/caregiver education and counseling services provided as a core element of your program?

17. Do families and patients associations/support groups collaborate with your center?